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ABSTRACT

The report presents findings from interviews with 10 families with children (4-19 years old) with severe mental retardation and multiple disabilities regarding the need for technical aids and adaptations in their homes. The following areas are addressed and examples of solutions proposed: hygienic aids (hot water adaptations, travel adaptations, bath hoists, toothbrushing); eating aids (bib laundering, insufficient fluids, dining chairs); sleeping aids (vertical adjustment capability, shaped supports); communication aids (comprehension difficulties, insecurity at night, TV and radio); sitting aids (improved wheelchairs, head support, the need for stimulation); mobility aids (electrical wheelchairs, specially made overalls, car transport); and recreational aids (outdoor bathing, swings, the role of music). Notes on appearance of the aids and their storage conclude the report. (CL)

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THE AIDS REQUIREMENTS OF CHILDREN WITH SEVERE MULTIPLE HANDICAPS AND THE PEOPLE LOOKING AFTER THEM

Gerd Andén

Translated by Graeme Robertson

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The Swedish Institute for the Handicapped
March 1984

THE AIDS' REQUIREMENTS OF
CHILDREN WITH SEVERE MULTIPLE HANDICAPS
AND
THE PEOPLE LOOKING AFTER THEM

Results of interviews with 10 families
by
Gerd Andén

C O N T E N T S

A new and relatively unknown care situation	2
Introduction	4
Persons Interviewed	6
Hygienic Aids	13
Eating Aids	30
Sleeping Aids	40
Communications Aids	49
Sitting Aids	60
Mobility Aids	73
Recreational Aids	93
Hoisting Aids	103
The Appearance of the Aids	108

A new and relatively unknown care situation

The Swedish Institute for the Handicapped is the central body dealing with aids for the disabled in Sweden. The Institute's activities require that it obtain a broad overview of the use of aids. The Institute is charged with taking into consideration the social, psychological, pedagogic, medical and economic aspects of aids and their use as well as technical matters in its work with aids and other measures for the handicapped. This is to obtain an overall view of possible measures that could be used.

Many categories of occupations come into contact with the mentally retarded and the intellectually handicapped. Educational backgrounds and knowledge of mental retardation vary widely which we believe is one of the reasons why the mentally retarded as a group are so poorly equipped with aids when compared to other groups of handicapped persons.

An increasing number of even severely handicapped children are now living at home, where they are looked after by their parents. Even the institutionalized children are being moved into integrated group homes in ordinary dwelling houses. This has resulted in a substantial increase in the need for different aids for severely handicapped children.

In order to obtain a better idea of the aid situation the Swedish Institute for the Handicapped initiated a study of ten families, all of whom look after their severely handicapped children at home.

As the situation that these families are in regarding the care they provide is new and relatively unknown, this material should be of value to everybody involved in some way with rehabilitation work. The interviews can no least be of support and provide ideas to parents in similar situations to the ones interviewed.

The Swedish Institute for the Handicapped would like to warmly thank Gerd Andén who performed the interviews and wrote the report.

The Swedish Institute for the Handicapped

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Introduction

A survey was made of severely mentally retarded children and young people and those with severely impaired mobility living at home in the Stockholm County Council administrative area as a part of the project. The survey took the form of a questionnaire sent to the regional offices of the Social Welfare Board for the Mentally Retarded and covered people aged between 3 and 23. From the number of replies received it was determined that there were about 140 children in this category.

In addition to being severely mentally retarded and having severely impaired mobility, the children have further disabilities:

Visual impairment	45%
Impaired hearing	27%
Cramps	57%
Mental isolation	39%

About 10% replied "Don't know".

The observations and information contained in this report are based on interviews conducted with 10 families, and we owe them a debt of gratitude. I visited these families and was received with hospitality and great interest in their homes on several occasions. Here I personally saw the need to modify dwellings and introduce technical aids that would enable parents to take care of their children in satisifactory manner.

I had the pleasure of meeting the disabled or handicapped children in all the families. They are all personalities that made a strong impressions on me, each in their own way. The children displayed a lot of patience during my visits, as they had to wait their turn for their parents' attention.

The conversations with the parents were recorded on 39 cassette tapes. During the course of the work I have been able to refer to them to remind myself of the important points made by the parents.

I would like to extend my warm thanks to all the parents and children that participated in the study. It is my sincerest wish that as a reward for their efforts things may be made easier for them in the future and that the children's need for aids will be met.

Gerd Andén
Project Leader

What aids do severely handicapped children and those looking after them require? To what extent do dwellings need to be adapted? Gerd Andén has looked for the answers by interviewing families in their homes.

PERSONS INTERVIEWED

Aim

The aim of the study was to investigate the need of, primarily, technical aids by the most severely handicapped children and young people that live at home with their parents. The people working on the project have tried to produce suggested measures that enable families that have severely handicapped children living at home to lead normal lives as though the child was not handicapped. What can be done using technical aids and what has to be performed using human resources?

Persons interviewed

The ten families that were interviewed were categorized on the basis of the children's ages, etc., so that they ought to be representative for the group. The children were between 4 and 19 years old. We have assumed that the need for assistance and aids by younger handicapped children is not that different from a normal child of the same age group. At the age of 19-20 the child should have grown to the extent that he or she has an adult's needs for aids. All the families live in the county of Stockholm. Perhaps their need for aids is met better than a similar family living in a sparsely-populated area? The most important thing from the point of view of the study, however, is that the needs of these ten families are representative of the group as a whole. We have no reason to doubt that this is so.

Five of the children are boys and five girls. The height and weight of the children has more bearing on the need for aids than their ages. They weighed between 18 and 88 lbs. (8-40 kg) and their heights varied between 33 and 65 inches (85-165 cm) and they did not follow the normal scale for chronological ages. They broke down as follows:

Age	4	6	7	8	9	11	16	17	19
No. of children	1	1	1	2	1	1	1	1	1
Child's weight (kg)	15	8	14	18 23	25	30	25	35	40
Child's height (cm)	110	85	115	130 130	140	130	145	150	165
Girls				x	x	x	x	x	
Boys	x	x	x		x				x

Disabilities

All the children were paralysed over their entire bodies. They have major brain damage. None of the children can walk, stand or sit without support. They cannot use their hands normally, i.e. grasp or control their fine motor movements. They do not possess any inherent bodily deformities, e.g. the lack of any visible part of the body. The majority of the children have scoliosis and experience great difficulty in sitting straight, even with support. Some of them have one hip dislocated and several risk this occurring. Six of the children have spastic paralysis and some of them have very high tonus, i.e. are in a state of persistent excitation. Some of them have intermittent tonus and oscillate between contraction and relaxation. The size of the majority of the children's heads is too small (microcephalia). The majority of the older children have severe contractures in the arms and legs and none of the children can hold their trunks upright without support - many of them cannot even hold their heads up without special supports.

Four of the children have verified major impairment to vision. Probably all of them have a secondary reduction in vision, because none of the children can have obtained a real concept of space or a true assessment of distance or height due to the fact that they cannot turn their bodies or heads and position themselves vis-a-vis their surroundings. In other words they presumably cannot use their

vision in the normal way because they have not obtained the background that normal children have when their sight develops. None of the children can move themselves, not even using a wheelchair. Only one of the children has verified impaired hearing.

All ten children have epileptic cramps and receive the traditional cramp medication. Intellectually they are all severely mentally retarded, but it is very difficult to determine the degree of their intellectual handicaps due to their severe multi-handicaps and motor paralysis. None of them can talk or make themselves understood using traditional means, sign language, etc. It is highly probable that six of the children are highly mentally retarded on Level A. The parents do not believe that they understand speech or pictures other than signals. A further three are also possibly on Level A but could be on the border to Level B because sometimes one can believe that they understand speech and often react adequately to their environment. Their reactions are not sufficiently consistent to enable one to be certain. One of the children, however, understands what one says and shows this so clearly that it can be stated with certainty that this is a question of at least a Level B and not a Level A. (For division into A, B and C levels, see "The Intellect and Intellectual Handicaps" by Gunnar Kylén, 1981, published by the Swedish Institute for the Handicapped and the ALA research foundation of the National Association for Retarded Children, Youngsters and Adults dealing with adaption to life and work).

In terms of the abstraction levels of the intellectually handicapped, the first level is called Level A, the second Level B and the third Level C.

At Level A one experiences emotions and concrete reality. One experiences - compares - and recognizes.

At Level B pictures and the spoken word are understood. Impressions are arranged into small, concrete categories. One learns to find the way in places where one has often been previously. Amounts, two, three and perhaps a few more are understood. One obtains a better idea of time, under-

standing to-morrow, when we have eaten, etc.

On Level C the written word is understood. Impressions are arranged in general categories. Things can be changed in one's thoughts, concrete thought operations can be performed.

Behaviour

Four of these severely mentally retarded children showed stereotype behaviour or autism, either of the "continuously repeating certain movements" type or "isolationism" from their surroundings. It can be guessed that this can have been caused by lack of stimulation and is not solely due to mental abnormality.

Six of the children have great difficulty in swallowing, and none of them can chew or move their tongues in the normal way. Only one of the children can suck - the sucking reflex remains from infancy and the child still sucks on a bottle with a rubber teat.

Worsening the handicap

The children in the survey therefore have major physical disabilities. They are severely multi-handicapped and have major impairments to mobility, with the result that they have to receive assistance with just about everything. They must also be constantly kept under observance. They lack the normal protective reflex actions to help themselves should they fall. In emergencies they can only summon help by screaming. All of them are totally confined to wheelchairs. Their severe mental retardation further worsens their motor handicap so that perhaps they cannot even use the small movement capability that they do possess. The motor disabilities prevent the children from acquiring many of the experiences they need to be able develop intellectually. In this way their intellectual handicap is worsened unless human and technical aids can be used to give them the experience required.

Housing and schooling

All ten children live permanently in their parents' homes. Two of the families comprise single parents. Eight of the children have siblings. Two of the siblings have left the family homes - one of them has children of his/her own.

One of the children receives no schooling outside the home and only special tuition is provided at home. The others make trips daily, unless sickness or some other obstacle prevents it, to join in activities at school. Educational types break down as follows:

Type of schooling	No. of children
Special tuition at home	1
Segregated kindergarten	1
Individually-integrated kindergat.	1
Segregated training school	3
Local-integrated training school	3
Activities training	1

Help requirements

All these children need continual assistance in the form of human resources. It is primarily the family that is the aid that is used for the majority of the time with the children.

Other regular human resource help that these children receive is that provided by local authorities home-helps, treatment by physio-therapists and help at school.

Max. permissible relief (regular) for parents, i.e. the child is in the care of someone other than the parents.

Per week:	For the 10 children
kindergarten/day care centre	= 40 hours approx.
kindergarten/day care centre	= 25 hours approx.
training school + child help 8 hours + 1 afternoon at recreational centre	= 40 hours approx.
training school + child help 12 hours	= 37 hours approx.
training school + afternoon centre	= 40 hours approx.
training school + afternoon centre	= 40 hours approx.
training school + home-help 5 hours	= 35 hours approx.
training school + home-help 8 hours	= 35 hours approx.
home tuition + home-help 7 hours	= 9 hours approx.
activities training	= 35 hours approx.

Only the home-helps can take over from the parents when the children are at home from school at the holidays or due to sickness. During family holidays four of the children are usually lodged at a student home for the physically handicapped. One of the children is lodged over the short-term regularly at a central nursing home and another at the temporary home of the Social Welfare Board for the Mentally Retarded in emergency situations. Three of the children have never been temporarily lodged at institutions, one child lived in a nursing home for three years, but for the last several years has resided in the parents' home. All parents require more relief in the home. This is particularly true during the evenings and at weekends and during the time when the child or someone else in the family is sick or similar.

The Social Welfare Board for the Mentally Retarded or a section for the physically handicapped provide physiotherapy in some form every week for the children, although this is only available occasionally for a couple of them.

2 children receive the assistance of a logopedist, 6 children sometime in the past have had the help of a logopedist and 2 of the children have never been aided by a logopedist (for food situations).

Dwellings

Eight families live in detached houses, three of which are designed and constructed with the needs of the handicapped child in mind. A further three families have purchased and moved into detached/semi-detached properties solely because of the needs of their handicapped child. Two of these have purpose-adapted houses and the third will be making these alterations.

Two of the families live in block of flats - both have been adapted to a degree. Two families live in houses that have not been adapted and which were not purchased for the sake of the child.

HYGIENIC AIDS

In Sweden the normal standard of dwelling means that we have a number of aids to help us with our personal hygiene. Under special conditions, e.g. when on a hike in the mountains or on a camping holiday, we can manage with a basin, soap, hand towel, toothbrush and toothpaste, toilet paper and tampons.

We arrange our hygienic equipment so that we can keep ourselves clean in a simple way. For instance, our towels are hung up within reach of the wash basin or shower, we have soap dishes, toothbrush glasses and a mirror at the wash basin, etc.

We have other aids to help us keep our hair clean and well cared for. We have special, self-evident aids to keep our mouths and teeth clean and healthy.

The handicapped children studied in this survey need all this just the same as everybody else!

Compensating aids

In order to compensate for their disabilities they need a human aid in order to perform that which the rest of us do with our hands, e.g. wash and dry ourselves. Furthermore they require all the technical aids that they would have had access to if they had been normal in order to come up to our "standard". Now they often cannot use the hygienic aids that are available in homes for "normal" family members. They cannot stand up under the shower, they cannot sit on the toilet, etc.

This seems to be the major reason for personal hygiene being so much hard work and so time-demanding for these children and the people who look after them.

The children require additional technical aids to adapt the standard aids in order to make use of the hygienic aids that are available as standard in our dwellings. This has to be performed in such a way that both the handicapped child and the other members of the family obtain hygienic equipment of a satisfactory standard. The lack of such adaption means that several of the older children are washed and "treated" in bed in the same primitive way as others use when on a camping trip. The parents fetch water from the bathroom in a basin and wash the children with a wash cloth.

Universal incontinence

None of the ten children can sit in the bath, stand in the shower or sit on the toilet. Neither can they rinse their mouths or spit when having their teeth cleaned. All of them are incontinent and always wear diapers because none of them can express their need to go to the toilet. Only one of the children defecates involunatarily but none of them can sit on the toilet without, in some cases, the parent holding them in position.

Six of the families have made varying conversions in the bathrooms to adapt them to the needs of the child. The families with the three youngest children have not done anything about this, but one of the families plans to make changes in the immediate future. One of the older children's families has not adapted their dwelling, but they plan to construct an extension to the building with a large room and a large bathroom for the handicapped child.

Hot water

As none of the children are capable of protecting themselves from excessively hot water and they cannot even indicate by signs that the water is the right temperature, the majority of families would like mixing valves that allow the hot and cold water to be mixed at a preset temperature. Five of them have mixing valves that they

are satisfied with, and a further two families would like such an appliance installed forthwith.

None of the children can wash themselves - they have to be washed by someone else. Every day a large number of disposable wash cloths of cellular plastic or paper are used and it is felt that these should be supplied free of charge in the same way as the diapers.

Heavy loads

The young children are often washed in the same way as one washes an infant, i.e. the mother sits the child on her knee in the bathroom or the child is washed on a little diaper-changing table in the bathroom or bedroom. In such cases it is still possible to carry the child to and from the washing site without too great an effort. Once the child reaches school age and weighs over 33 lb. (15 kg) the hygiene situation is regarded as much more work than previously. The need for a diaper-changing table in the wash room becomes great.

Only one of the families, that has a specially constructed house with a large bathroom, has a sufficiently large daiper-changing table that is free-standing in the bathroom near the wash basin, etc.

Three of the families have installed "Rehab" shower tables over the bath tub and hope to be able to use this as a diaper-changing table as well. But this seldom proves to be satisfactory as it is often wet and clothing, etc., becomes damp when changing the child there. One of the older children is still most often washed and dressed on the parent's lap in the bathroom. The majority of the others are washed in the bathroom and then carried or wheeled - wet - to the bed where they are dried and dressed. One of the children has a shower carriage that is wheeled between the bedroom and the shower room which works very well once the building has been converted.

Two of the oldest children are often washed in bed and only use the bathroom when they shower or bath. The parents of the older children wish they had a free-standing diaper-changing table in the bathroom so that they could place the child there on dry towels directly after a shower or bath for drying and dressing. A combined shower/diaper-changing table cannot work as well for this purpose as it is wet after use.

Time-consuming ablutions

The young children never shower - they bath in the tub together with their parents. But even these families wish they had the capability of giving the child a shower. For instance, a shower chair to put in the bath tub, or a shower table, because it takes such a long time to bath the child every day.

It seems to be more and more important to possess a shower capability the older the child is, something that can be used every day and allows for rapid and easy operation. Teenagers produce large quantities of urine, they have greasy hair, they perspire copiously and the girls start to menstruate. Just like everbody else they need to be able to take a shower so that they are clean before starting a day at school.

Showering and washing the whole of a child's body is performed easiest and quickest when the subject is reclining on a shower table which should be at a suitable working height for the person bathing the child. Eight of the families have tried to solve this by arranging some kind of shower table above the bath tub or, in one case, by using a shower carriage. Three have wooden shower planks over the bath and four have shower tables consisting of nylon fabric stretched over a steel framework. The shower carriage, which in its existing configuration takes up a lot of room in the bathroom and the dwelling, works very well for the family that uses it, but would not be suitable for the others. Instead what is required is a functioning shower table over the bathtub. The "Rehab"

shower table is too short for the larger children, but the others like it. It is felt that it is a substantial benefit that it is attached to and can be folded up against the wall.

Water, water everywhere ...

The majority of the children think that it feels cold and uncomfortable to lie direct on the shower table. One of the children, who makes serious and violent spastic movements of the arms and legs, often bangs his limbs against the walls, pipework and taps over the bath. Most of the parents experience the problem of water spraying over them and the entire bathroom when they are giving the child a shower. They would therefore appreciate a soft shower mattress to lay over the shower table. It would preferably be perforated to allow water to run through and should have edges that prevent the child from hitting himself - and the area being subjected to an impromptu showering. Moreover, several small cushions are needed as a protection on the shower table when only a part of the child's body is to be washed. For instance, when washing the child's hair. In such a case it should be possible to lie the child on a cushion that covers the shower table except the area under the child's head - in other words up to the child's shoulders. In this way one could hopefully wash the child's hair without wetting the rest of the body. The same thing applies when it comes to washing the child's bottom. A dry cushion would then be placed under the upper body while showering below the waist.

The girls do not use any particular tampons - the ordinary diapers absorb the menstrual discharge. As they cannot use a bidet, it is important that these girls have a functioning shower capability which enables them to shower just the pubic area during menstruation.

The importance of the morning shower

One family who lives in a two-storey house with the child's bedroom on the ground floor and the bathroom upstairs, has a special problem with their child's hygiene. The child is incontinent and can therefore be in acute need of a shower in the mornings. There is a chair lift up the stairs to the upper floor, but the child has to be sat on the attendant's knee. Lifting up a large child who is covered in foul-smelling excrement from the bed, sitting with the child on one's knee in a chair lift, carrying the child to the bathroom to be placed on a shower table before ablution can start - this is an impossible solution to the problem. The current alternative which is being used is to clean the child in the bed using a basin with water and wash cloths. For this family - and certainly many others - a little shower carriage would be of great help. With this it would be possible to lift the child out of the bed directly into the carriage and wheel it to the wash room which would be sited on the ground floor. A discharge pipe could be connected here as could a shower hose from the water taps to shower the child clean quickly and with greater comfort to the child and attendant. The carriage could then be wheeled back into the bedroom where the child is usually dressed. It should be possible to fold up the shower carriage and store it in a cupboard until it is required again.

Mixing valve
Wash cloths
Diaper-changing table
Shower chair
Shower table
Shower mattress
Shower cushions
Shower carriage

Hygienic aids
Bath chair
Bathing harness
Mirror
Toothbrush
Diaper pins
T-shaped diaper
Toilet chair

A perforated shower mattress with high sides for the shower table would prevent the surrounding area being subjected to an impromptu showering.

Going on a trip

It should be possible for the other members of the family to make use of this type of shower aid on occasion, e.g. in a weekend cottage or away visiting someone. Hygienic aids are available at hotels, at relatives' and friends' homes and in holiday accommodation. For the families with handicapped children going on a trip can often be unnecessarily laborious. They cannot enjoy their recreational activities to the same extent as others, because caring for the child requires more time and is more work than at home. This can result in travel being avoided or that one tries to place the child temporarily with someone else while the rest of the family goes away. Therefore the families need additional aids - over and above those in the home - e.g. hygienic aids, that can be taken with them when making a trip. Most of the families would like to travel with their handicapped child if it is possible in practice to manage a holiday together.

A large shower table presents transportation difficulties - a shower chair would be a simpler solution. The younger children can sit on their parents' knees and be showered and these parents feel that they do not need a shower chair. Three of the oldest children have such severe scoliosis that the parents feel that it is not possible to get them to sit in any form of shower chair - they prefer to wash the child in a supine position. The collapsible shower carriage described earlier could be the solution to their problem. However, several of the families feel that a collapsible shower chair with soft supports for the entire trunk of the child's body would be of great help. It should be a combined shower and toilet chair.

Increased bathing comfort

All the children like bathing in warm water. They relax under these conditions and enjoy a hot soak. For this reason the parents try, when they can manage it, to help the children have a bath sometimes. The young children take a bath together with their parents and they need the body contact and sense of togetherness that this provides. As it takes a long time to bath with the child every day, one of these families has expressed the wish that there were a bath chair for the child so that now and then the child could be left alone to sit and play in the bath. The bath tub would have to be raised so that standing and bending over the tub to help the child bath does not become unduly laborious for the parents.

The older children's scoliosis makes it difficult for them to sit in the type of bath chair they have tried to use, e.g. the "Hasi" bath chair. They slip out of the sides of the chair. The bath tub is to small for them to be able to bath together with their parents, and moreover they like to lie and float freely in the warm water. Often it takes two adults to give them a bath. The child has to be lifted into and out of the tub and has to be supported in the water. Some of the children are very heavy when they get cramps, for instance, or throw themselves backwards. It is difficult to give the child

the opportunity and the time to "play" in the water while continually bending over the edge of the tub and holding the child. These children have a real need to experience water and moving around in water, and for this reason they need to have baths more frequently - not just in order to keep themselves clean. What the families want is a bath chair with an anti-slip coating that children with severe scoliosis and no control of their heads or the trunks of their bodies can sit on in the bath tub. In addition it is important that the families with older children have functioning bathing harnesses or straps running in an electrical hoist mounted on the ceiling.

Bath hoists

Five of the families have "Akema" ceiling-mounted hoists. Four of them have the hoists installed in the bathroom over the bath tub. One of the families uses the hoist when bathing the child, the others feel that it is so difficult to use the cumbersome harness provided that they cannot use the appliance. But even the parents that use the hoist in the bath wish that the harness were much easier to put on and take off. What is wanted is pliable straps that can easily be fitted or removed in the bath, that are water-resistant and dry quickly. It should be possible for one assistant to put the straps on and take them off and they should be able to wash all of the child's body with the straps in position. It should be possible for the child to sit suspended by the straps in the water in such a position that ablutions can be performed.

After a bath or shower there has to be somewhere for the child to be dried and dressed. A diaper-changing table is often the most suitable place. The young children are wrapped in a towel and are carried to the diaper-changing table or bed, or they are dried and dressed on the parents' knee. A major problem with the older children is that it is no longer possible to do this. It works well if, as

with one of the children, there is a free-standing daiper-changing table in the bath room. The child can then be placed directly on this table from the bath. Some of the families attempt to use the shower table that folds down over the bath tub after the bath as well as during it, but this seldom works well. It is difficult to hold the child while folding down the shower table from the wall, everything gets wet, etc. The other families carry the wet children from the bath to the bed or diaper-changing table where they are dried and dressed. One of the parents in the single-parent families usually lays a towel on the bathroom floor and dries the child there.

Problems despite advice

Most of the families do not have the space for a large, free-standing diaper-changing table in the bathroom. One of the families was resentful because they built their house with the needs of the handicapped child specially in mind only to find that the bathroom is not large enough. When the house was built the child was so young that they were incapable of foreseeing the amount of space they now require. Despite advice from architects, work therapists, physiotherapists, etc., they were not informed of this problem and the amount of space they would require in the future with the result that a minimum of two adults are now needed to bath or shower the child and manage the transportation to the diaper-changing table which is situated in the bedroom.

Shower/bathroom too small

The family that has a shower carriage for their older child does not face this sort of problem. The child is lifted from the bed and onto the carriage, it is wheeled to the shower room, the child is showered and wheeled back into the bedroom where drying and dressing are performed on the bed. There is an electrical ceiling-mounted hoist above the bed. The other families do not have a large enough shower/bathroom or wide enough door openings to enable them

use this type of shower carriage without necessitating major conversions to their dwellings.

One family would like to have a simple collapsible daiper-changing table on wheels that could be placed in the hallway outside the bathroom door when the child needs to be dried after a shower or bath. Some people feel that the problem could be solved by being able to place the back- and foot-rests of a wheelchair horizontally so that the child could be laid on towels on it and dried there before being wheeled to the daiper-changing table or bed to be dressed.

The parents wash the children using wash cloths, often of the disposable type. Some of the families prefer paper cloths, others cellular plastic. It is frequently felt that the wash cloths that are commercially available are too thin and too small, so several are used at once. One mother buys dish-washing cloths and cuts them down to size.

Conceptualization of the body

The children often have difficulty in obtaining a concept of their bodies because they cannot feel all of their bodies with their hands, see all of their bodies even if their vision is not impaired, neither can they move normally which gives them the normal sensory impressions over their entire body, etc. Of some help here can be that the child, if possessing sight, can be give the chance to view a full-length reflection of him/herself in a mirror which could possibly be mounted alongside the diaper-changing table or bed. Then the child can observe what the parent is doing when e.g. washing and dressing is being performed, even down to foot level, and it is easier for the child to participate.

It is important that the diaper-changing table is at the right working height for the parents and that diapers, hand-towels, clothes, etc., can be positioned within reach of the table. Several families have solved this well by placing crates or boxes under the table. Diaper-changing tables have been constructed by buying a table-top and two drawer pedestals, for example, and placing a terry-towel covered mattress on the top. One family that has a young child has mounted an normal-sized bed on cupboard pedestals and made a child's bed of one half and a diaper-changing table with cushions of the other half.

Three of the older children are attended to in their beds, which have been raised to a suitable working height. Several of the families use a disposable hygienic mat on the diaper-changing table or bed when washing the children. The parents are pleased that these are free of charge.

Teeth cleaning

The children covered by this study require normal mouth and dental hygiene care, but the parents feel that it is difficult to manage this successfully. None of the children can rinse out their mouths or spit.

All the parents use an ordinary toothbrush to brush the child's teeth, but they do not use toothpaste because the child swallows instead of spitting out and cannot rinse after cleaning. Five of the children have swollen gums as a side effect of cramp medicines and it is therefore difficult but important that any cavities that form in the gums round the teeth are kept clean. Some of the children have great difficulty in cleaning their teeth because the touch of the toothbrush activates a reflex biting action. Another child often refuses to even open his mouth for the tooth-brush. These families feel that an electric toothbrush would be of benefit. Perhaps such an appliance would make it easier to get at the teeth and clean them and also massage the gums more efficiently.

Water through the brush

Possibly the problem of rinsing the mouth clean could be solved if there were a toothbrush that fed water through it into the mouth at the same time as the teeth were being brushed. Foreign matter would not just be brushed off, but the water would rinse the teeth at the same time and it could then either run out of the mouth or the child could swallow it. Such a toothbrush could be bought in the past from one of Stockholm's leading department stores, but in all probability is no longer sold in Sweden. This brush was equipped with a little container with fluid that was sprayed out through the brush when a button was pressed.

Six of the families expressed interest in such a toothbrush with a rinsing action. The absolute best would be a cordless electrical model with this rinsing action. Naturally the children would not be able to use this toothbrush either to brush their teeth, but the parents believe that it would be easier to keep the teeth clean and strengthen the gums using such a device. The boy who refused to open his mouth for an ordinary toothbrush has accepted cleaning using an electric toothbrush when he has had the chance to test it.

Diapers are insufficient

All ten children are incontinent. They cannot say when they need to urinate or defecate. Otherwise their urinary tracts and bowels work normally for their chronological ages. Some of the children suffer from constipation and periodically have to eat laxatives and foods rich in fibres. Half the children use "Microlax" enemas to initiate lower bowel activity when defecating. The others, with the exception of one, can manage bowel movements at specific times

without recourse to enemas. Only one child has involuntary bowel movement, i.e. the child has not been taught to defecate at a specific time of the day.

None of the parents believe that they could teach their child to indicate the need to urinate. They do not, however, feel that this is particularly important as the child cannot sit on a normal toilet seat anyway. All the children therefore urinate into their diapers and produce normal quantitites of urine for their ages.

The young children use ordinary standard diapers with an enveloping plastic binding intended for infants and sometimes standard T-shaped diapers. In one case the child has such violent spastic movements that the diaper always slides to one side and so the plastic binding is used on the sides. It would be easier to tie the corners of the binding across the stomach, but then the tying ends would have to be longer than those presently available. The size of diaper for young children is not always large enough to absorb all the urine held in an 8-9 year old's bladder. In such cases "night" diapers are used, even during the day. It is difficult to get the plastic binding to fit when the child gets a little bigger, but the next size up is far too big and the child becomes unnecessarily "swaddled". Such a large amount of plastic directly against the body is particularly uncomfortable for the child during the summer. What is wanted is a T-shaped diaper that could be worn under a pair of mesh pants, so totally avoiding the outer plastic binding.

Daiper chafing

It is a problem to find a satisfactory way to protect the clothes and surroundings of children aged between 11 and 19 years old from urine because there is no diaper that works for the large

amounts of urine involved. Moreover, these children are heavy and easily experience chafing and pain from lying on the knotted tying ends of the plastic bindings. All the families complain of the large amount of washing that has to be done daily as a result of urine-soaked clothes, bed clothes, etc. They attempt to solve the diaper problem by using various combinations of the types of diapers available. Three of the children still use "Lenina" night diapers. Either one or two "Lenina" night diapers in a "Maxi" enveloping binding. Regardless how the binding is tied up, and despite two thick diapers, urine still runs out of the sides. One family uses one diaper in a pair of "Vima" diaper pants and this has been found to be much better than the plastic binding for this child who has a sensitive skin and previously was prone to "bed" sores.

One parent puts several night diapers in a "wing" diaper which is held in place by a pair of mesh pants. This works better than all the combinations tried earlier, but is not completely satisfactory as it is difficult to put on.

A "wing" diaper and one or two "Maxi" diapers in a pair of diaper pants works as some sort of protection for one of the children, but is very cumbersome, hot and plastic.

Everybody wishes that they could have a diaper that worked for their children. For example, one T-shaped diaper of high capacity and sufficient size plus mesh pants. The large diapers that have been tried proved to be much too large, but too thin just at the place where the children urinate so that the urine runs off and out over the clothes at the side while the major part of the diaper remains dry.

Forced to return home

The child has to be laid on e.g. a diaper-changing table in order for the diapers to be changed when one is using several diapers and the enveloping plastic binding, for instance. This means that

if one is on a trip in the country or suchlike - perhaps shopping in town - it is impossible to change diapers without lying the child down somewhere. Toilets for the handicapped are of no use, even though they afford access by wheelchair, because they do not have a bed or similar flat surface.

Only one of the children has bowel action at any time of the day. The other children have learnt to defecate at specific times. Three of the children have tried custom-made toilet seats with supports for the trunks of their bodies, but so far none of them has worked. One family with one of the older children has tried tenaciously but in vain to find a functioning toilet seat for eight years. The child defecates without recourse to enemas at a specific time every day, during which time the mother's strong arms hold the child, who weighs about 66 lbs. (30 kg) in the air above a chamber pot. This works well for the child who has no problem whatsoever with constipation or the suchlike, but places an unreasonably heavy burden on the mother's back and arms.

A long time on the toilet

Two of the somewhat smaller children are held by their parents so that they are sitting on the edge of the toilet, propped up and leaning against their parents. These child can need to sit there for a long time - up to an hour sometimes - even though "Microlax" is used, and the parents regard standing in this way and leaning over and holding the child as a daily strain on their backs. Lying down to defecate is even more of a problem for the children because it is even more difficult to bear down and put the bowels into motion in this position.

The other children defecate lying down. In some cases the lower bowel is stimulated by inserting a thermometer or similar to activate the bearing down reflex action. The parents hold the children's legs

upwards and apart to assist the child in bearing down. It is usual that "Microlax" is used to initiate action of the bowel muscles. In some cases several doses are required every time and it takes even longer and is laborious for the child to bear down when supine.

Cannot manage everything

Seven of the families say they have a great need of a toilet chair that works for the children and enables them to sit and defecate on the toilet. In some cases there is a desperately urgent need because it is no longer possible to hold the child as is the case at present and the parents have no idea how the child is going to manage visits to the toilet in the future.

The children require toilet chairs adapted for their individual needs with a means of supporting their trunks gently but firmly and which enables them to lean backwards in certain situations. The support should be as soft and as pleasant and feel as secure as being held in "mother's arms". It should also be possible to adjust from a half-reclining to a forward-leaning position and a support should also be provided at the front against which the child can lean as required.

The preferred solution is a combined shower/toilet seat as mentioned above. It should be possible to wheel it into position over a normal WC pan or place a chamber pot underneath. It should be possible to disassemble it so that it is easily transportable and can be taken with the family on holiday, for example.

Most of the children are well looked after hygienically, but hygiene care takes far too much time and energy in most families. One of the reasonable requests made by the parents is that it should be possible for ONE attendant alone to provide the child with hygiene care and that it should not take much longer per day to perform this work for these children than for other modern human beings.

EATING AIDS

The ingestion of food and liquids in an enjoyable manner is taken for granted in our welfare society to such an extent that perhpas we seldom stop to consider how many aids we have acquired to enable us to do this.

The majority of the ten handicapped children covered by the study did not have a "normal meal standard". For their parents it is most often not a matter of making their meals a special occasion but rather an attempt to get nourishment and fluids down the child's throat. The reason for this is two-fold: the handicaps the children have can make it very difficult for them to eat and the majority of our ordinary eating aids cannot be used with some of the children and suitable replacements have not been found.

Chewing inability

None of the children can chew. All of them have well-developed teeth but they cannot move their tongues in their mouths normally in order to move the food around. They have paralysis of the throat, their mouths are severely spastic and/or they have far too sensitive jaw reflexes. None of the children can suck, with the exception of the youngest who still has the sucking reflex and can suck a baby's feeding bottle.

When the children are infected or the suchlike, the food situation becomes even more difficult. Sometimes it is impossible to get them to ingest sufficient nourishment and liquids and when they become seriously ill most of the children have had to be fed intravenously on occasion in hospital in order to weather a crisis. Even at home some of the children have required additional food in order to obtain

sufficient nourishment. In such cases Semper's foods for feeding through tubes, for example, are used with fruit or similar added for taste. During such periods it is very important for the families that they can receive counselling from a dietician on the child's food.

None of the children are allergic to certain foods - all of them eat ordinary food that is minced or made into a purée. All the children require assistance throughout the entire meal - they have to "borrow" their parents' hands in order to introduce the food into their mouths and hold liquid in their mouths and get it down their throats. For the majority of children a meal takes a long time - up to one hour. It is an important sharing experience for a family to sit and eat together, an occasion that every member of the family needs to experience. With the exception of some of the smaller children these handicapped children cannot sit at the dining table with other members of the family because, among other things, there is no room for the wheelchairs at the table. In some instances it is therefore usual that the parents do not get the chance to eat their food while it is still hot if they have to feed the child at the same time. Most often these children eat, i.e. are fed by one of the parents, before or after the rest of the family's meal time. Most often they do not eat at the dining table at all, but their food is served on a wheelchair table or in some cases on a worktop in the kitchen which is a more suitable height for the assistant than a dining table. It must be socially unfortunate and poor ADL training for the child that in this way meal times become an intake of nourishment rather than a shared dining experience.

Mashes and purées

The children's food has to be well minced up because they cannot chew. In some cases it has to be totally in the form of a purée depending on the degree of difficulty in swallowing. Eight families

feel that they need a mincer in order to provide their children with a varied diet, including raw vegetables and meat which is difficult to cut up or mince sufficiently fine with a knife and fork. Five families use "Moulinex Moulinette" blenders which they are very pleased with. This aid is no longer available free of charge and the parents which it were. Moreover a "canister" is required for the machine which would allow liquid foods, e.g. meat soups, to be cut up fine. The families that do not own a "Moulinette" do not give their children food that cannot be mashed with a fork. The "Moulinette" is a very important aid if these children want to eat the same sort of food as other families. Normal food mixers are far too large and difficult to wash just to mash up one portion of food.

All the children spill a lot of food during the meals. They do not have normal mouth movements and they do not close their mouths in the normal way. Liquids are more inclined to run out of their mouths than solid foods. They therefore all need bibs instead of napkins when they eat. In addition abnormally large amounts of heavy-duty household paper are used during the meals and all the families pointed out that this is expensive over the long run.

Bib laundrying

In three of the families with young children the parents feel that the use of plastic or terry cloth bibs that are purchased in normal shops still works well. The problem of bibs for the older children is both a problem for the parents from the point of view of the amount of laundry and makes a child unpleasantly conspicuous. The sight of a teenager with an infant's bib on is very singular. It is psychologically very important that the child be accepted e.g. in schools where other children are, and it is important for the parents as well.

At present the families are using terry towelling or old towels as napkins for the children, or they sew up large bibs of plastic cloth or terry cloth. These have to washed every time they are used or they otherwise come to smell badly of old food. Furthermore the bibs become miscoloured by the food so that even when newly-washed they never look clean after their first use and this can incorrectly be interpreted by people as unhygienic.

Unsuitable bibs

One child who sits upright but does not close his/her mouth when drinking, thereby spilling large quantities of liquid, uses disposable bibs that are purchased through the County Council. This is the only type of disposable bib that is known on the market. All the families have seen this bib in hospitals or schools and they all feel that it falls far short of meeting the children's requirements. Visually it looks freakish particularly for the children who are integrated in schools and eat in ordinary school dining rooms.

Appearance is very important if one goes out to eat in a restaurant. This should also be true in the home and in everyday situations and perhaps the children think so too, although they do not show it. For a child to have to wear a large white sheet that envelopes most of the body and makes a rustling noise when one moves does not mark the individual as normal at the dining table, and should be unnecessary. Moreover, the disposable bib does not absorb all the spilt liquid because it is too thin - the liquid runs off even though it is so large. In outdoor restaurants, for instance, the bib is like a sail that flaps around the child's head. It is easily torn and involuntary movement by the child can easily tear it into shreds.

Absorption capacity

Instead the parents would like to have a more robust disposable bib that can be thrown away after each meal. It could be made of the

same material as is used in hygienic undersheets, i.e. plastic with "paper pulp", with the same absorption capacity as a thin diaper. The collar could have a strech edge that provided a seal against the neck and which continued in ribbons to be tied at the back of the neck in order to prevent liquid running down onto the clothes under the bib. The bib should be coloured or patterned, with squares for example, in the same way as our modern paper napkins.

A rather large bib made of such material and of pleasant appearance is required when eating. A similar bib, but small as a collar, is required by some of the children to protect their clothes from saliva even between meals. If the child does not close his/her mouth and sits leaning forward then saliva is often discharged over the clothes. Several of the children produce more saliva and of a greater viscosity than normal due to their epilepsy medication and unless their clothes are protected by a little bib that can be changed frequently they are always wet from saliva.

Less laundry

The disposable items that are requested would reduce the large amount of laundry that the parents have to do every day and would make meal times more pleasant for both the child and the people in the vicinity.

As the child's meal does not start until the food has been minced or mashed and then takes a long time, the food gets cold before the child ingests it all. Several parents always have a saucepan of hot water standing on the table with the child's plate on it to keep the food warm. One parent still has Mothercare's plastic heated plate which can hold hot water, but it is too small, it cracks often and does not retain heat efficiently. Often the food has to be returned to a saucepan and heated on the stove several times during a meal.

Keeping food hot

The parents wish that the children could have a heated plate that could keep the food hot throughout the entire meal (up to one hour) and which, when necessary, could be placed directly on the hotplate to heat up the food after a long break in feeding. It is important that it looks like an "ordinary" plate for adults so that it looks pleasant when the table is laid and does not deviate more than necessary from the rest of the dinner set. It should also have a fitted cover. The disadvantage of heated-up food can be that some C vitamins, for instance, are lost. If the parents use a heated plate they should be made aware of this so that e.g. fresh vegetables are placed on another plate to one side that remains unheated.

The children are fed with a spoon, usually of steel and a large teaspoon or dessert spoon model. Some of the children have such a powerful bite reflex that they sometimes bite the spoon hard, particularly when someone they are not used to feeds them, and they risk damaging their teeth. These families would like to have a rather flat, large teaspoon of soft, thick plastic that cannot damage the teeth. Some of the families use "Mothercare" plastic spoons and feel that they work well but could be larger.

Liquids worse than food

Often these children have more difficulty ingesting liquids than solid food. As they cannot suck the liquid into their mouths, it is inclined to run out when the children flex their tongues, for example. The parents feel that it is more difficult to help their children drink than eat and for the uninitiated it can be very difficult sometimes to get and liquid down the child at all. Several of the children have very sensitive bite and vomit reflexes and the person looking after them has to resort to certain tricks to avoid triggering them. Often the parents have to measure how much liquid approximately the child takes in per day. The children cannot

say that they are thirsty and often the margins are so small that the child may be receiving too few fluids.

The youngest child still sucks from a feeding bottle and it is not difficult to get liquids into the child in this way. Of the older children there are three that can take in liquid from an ordinary glass, although not without difficulty. One of the children spills so much that two glasses have to be used to provide that which is contained in one. None of them can form their lips round the edge and drink without spilling. Some of the children use the mugs with spouts that are employed to pour liquid into small children's mouths and two of the parents are very concerned because the Stilles medical supply company is no longer marketing its "spout". They have even considered advertising to buy second-hand "spouts".

Insufficient fluids

Three of the children are fed liquids by spoon, but experience difficulty in obtaining sufficient fluids in this way. The parents of the children who do not "drink" out of an ordinary glass requested a special special mug of transparent plastic for the children. It should have a sealed cap so that the mug with the contents inside could be taken on a trip, etc. The mug would have a lip with a broad spout so that small quantities could be poured into the child's mouth at one time above the tounge in order to make it easier for the child to swallow before the liquid runs out of the mouth again.

It is important the parents of the children that are difficult to feed obtain regular counselling from a logopedist. The purpose perhaps is not so much to train the child to suck and chew, but to be able to ingest nutrients and liquid in the most pleasurable way possible within a reasonable length of time at every meal.

The large "sheet" model disposable bib is thin and does not absorb spilt liquids, it tears easily and involuntary movements by the child easily tear it into shreds. The parents would like a more robust disposable bib of pleasant appearance.

Purée maker
Bib
Disposable bib
Heated plate
Flat spoon
Special mug
Supports
"Dining chair"

Relaxing in the parent's lap

It is very important that the children sit correctly during meals. Some of the parents prefer to feed the children with them sitting on their knees, even if they are big. This is because the children relax best in this way and they can be supported to prevent them from tensing their bodies incorrectly. It also allows the child's head to be held in the correct position.

Aids should be available that make it easier for the person looking after the child at mealtimes. Possibly a support that could be attached to the arm of an ordinary chair which could be inclined while attached to the child during the meal when the child is sitting on the parent's knee. Several parents want such an aid which they consider is important for the younger children. Once the child grows bigger one has to become used to sitting in a wheelchair and eating. However, this is conditional upon being able to adjust the wheelchair so that a suitable eating position can be obtained for the child. In addition it should also be vertically adjustable so that the person feeding the child, who is sitting next to the child on an ordinary chair, can sit comfortably without having to lean over the child or sit twisted because the wheelchair cannot be got under the table.

Dining chair for mealtimes

Another variation is that the parent sits on a rotating, vertically adjustable chair, like an office chair, when feeding the child. The disadvantage of this system is that one cannot travel with the "office" chair and the capability to vertically adjust and swivel the wheelchair is still needed in many situations. Several of the mothers interviewed would like a "dining chair" because it is not possible to adjust the child's wheelchair as required. The mothers get back aches during the meals because of the uncomfortable sitting position they have to adopt in order to feed the child.

The severe handicaps these children have make mealtimes one of the most difficult periods in the families' daily duties, but technical aids could make the situation easier. The human-resource aid and great patience on the part of the person looking after the child and the child itself are, however, the most important prerequisites for providing these children with food and drink.

SLEEPING AIDS

The majority of people have a bedroom of their own to allow them to sleep undisturbed. Just about everybody in Sweden has their own bed chosen from the range available on the furniture market. One buys a bed for oneself or one's child that is suitably long and wide, which is the right height and has a hard or soft base - all according to the individual's tastes and needs. We buy a suitable mattress for the bed and tasteful bedding and bed linen.

The young children covered by the survey have beds custom-made by the families that are satisfactory, e.g. ordinary beds raised up by standing them on drawer pedestals with railings along one side to prevent the child falling out. One of the children has insulation on the inside of the railings to avoid injury when experiencing cramps or violent movement.

Working height and width

For the older children it is very important that the bed is raised or can be raised to a suitable working height, even for those families that do not use the bed as a diaper-changing table for the child. Spastic paralysis and cramps mean that the children require some form of protection along the side of the bed to prevent them falling out of a bed of normal width. They require a special base for the bed which can be adjusted into the sitting position to enable the children to sit up in bed without the parents having to hold them.

This is of great importance to some of the children when they have a cold or stomach trouble. The majority of the older children have beds of normal width of 31 - 35 ins. (80-90 cm) that are raised on blocks, have side railings and a special base with manually adjustable backrest. The manufacturer is Bedco or Scandiform. The side railings on the Scandiform model are difficult to remove. Otherwise the parents are rather pleased with these beds. Two of the familes also have Bedco bed jacks under normal beds and are pleased with them.

However, most families wish that the beds were wider, even if the child is small, so that when the child needs consoling they could lie alongside without having to take the child into their own bed. As the children cannot, with few exceptions, turn over by themselves, the parents have to do this during the night. This is easier if the bed is wide because then the child can be rolled over like a log without having to return him/her to the middle of the bed after turning.

It is of great help to be able to raise the bed into a sitting position when the child is sick and is one of the conditions required to permit eating and drinking in bed.

Vertical adjustment capability

One of the families that has a bed that does not have an adjustable backrest would like a separate backrest that they could use when the child was sick and needed to sit up in bed.

The bed that seems to be ideal for the majority of the older children is a wide bed that has a normal appearance and does not look like a hospital bed. The bed should have an electrically-operated variable height mechanism, an electrically-operated backrest mechanism to allow the child to sit when required and should be easy to move on castors. When the parents need to lie alongside the child then the bed can be lowered to the same height as the parents' bed which can be positioned alongside so that the child can obtain the necessary bodily contact and comforting. One example of a family where this is very important is that in which the child is paralysed, deaf and blind. When the child becomes upset and perhaps has severe cramps, the mother has to provide consolation by lying close to the child and giving bodily contact, because she communicates with the child through "feel".

The amount of laundry in the families is large. Even with disposable sheets, ordinary cotton sheets have to be used so that the child has something more porous to lie on. All the families would like to have a soft, plasticized hygiene sheet that the child could lie directly on.

Wider bed
Backrest
Side railings
Hygiene sheets

In three of the families the child shares a bedroom with one of the parents in order to be able to receive assistance during the night. In several families the mother often spends large parts of the night in the child's bed in order to be on hand when the child vomits, needs comforting or has severe cramps, which often stop when the child feels the security of the parent's embrace. Periodically the nights are a difficult time for most of these families who feel continually worried that something will happen to their child while they are asleep.

Lack of space in bed

As the beds that the children have are of normal width, 31-35 ins., it is crowded and uncomfortable for both the child and the parent to lie in the same bed. The majority of the parents therefore would like a wider bed for the children, in some cases a double bed. If there is not an extra bed made up beside the child for the parent then making up a bed during the night when the need becomes acute is not feasible and the mother ends up lying in the child's bed.

If the bed is not wide enough to be sure that the child will not fall out when experiencing cramps or similar, then it must be provided with side railings. Most often there is a removable railing running along the side which produces new problems. If the railings are covered with a soft, protective material then the child cannot see out from the bed, which is important if the child has vision. If there is no soft covering on the railings there is a risk that the child can poke out an arm or a leg through them with severe injury as a consequence. Perhaps plexiglass could be mounted on the railings?

Some form of hygienic under-sheet is needed in the bed as all the children are incontinent and also discharge saliva through their mouths when they lie on their stomachs in bed. Most have the "Mölnlycke" sheet, a disposable hygienic sheet, that is laid across

the bed and is tucked under the mattress. One family uses this directly underneath the child. All the others have a cotton sheet or a sheet of terry-towelling on top because the hygienic under-sheet makes too much of a rustling noise, is too plasticized and can easily be torn. Lying unmoving directly on a hygienic under-sheet is very uncomfortable because the plastic, which is only covered by a thin layer of paper, causes the body to sweat.

Using the hygienic under-sheet to protect the mattress underneath a cotton sheet or piece of terry-towelling works reasonably well, but somewhat misses the point as there is still a lot of laundry every day, even though the hygienic under-sheet is disposable. The "Stora Kopparberg" disposable hygienic sheet seems to work better. It is of a more robust, softer paper and plastic matrix and the families that use it say that it is not so easily torn. But even this is put under a cotton sheet in order to give the child something more porous to lie on. One family now uses a plastic terry cloth sheet underneath the child which they wash daily. They previously used the "Mölnlycke" disposable hygienic under-sheet, but when the child moved in bed at night the mother, who sleeps in the same room as the child, could not sleep for the noise. Another family prefers to use a rubber sheet under the lower sheet.

Lying in the "right" position

All the families would like a hygienic sheet of the same quality as the soft, plasticized hygienic under-sheets that are available on the market, that the child could lie directly on top of. It should be large enough to tuck in round the sides of the mattress so that it stays in place even when the child is turned over, for example. This would contribute greatly towards reducing the amount of laundry and would make life easier for the child who would avoid the rashes, etc., that result from lying on a non-porous surface in bed.

Three of the children move around in bed and can turn themselves, at least to the extent of changing between lying on their backs and lying on their sides. The other seven children cannot change their positions when supine at all and have to be helped to lie "correctly" at night. Cramps and involuntary spastic reflex actions can mean that they end up in uncomfortable positions that they cannot rectify themselves, e.g. they flex backwards in an arc with their legs crossed and their heads pulled rigidly back. Due to their scoliosis and possible hip joint luxation (dislocation) their bodies try to twist into incorrect reflex positions if the child does not receive the correct type of support. Seven of the children need this type of support in bed. Some of them have sand bags which chock them up so that they can lie on their sides without rolling over, others use ordinary pillows that are bundled up and pushed underneath the child in a suitable way, others have soft toys that hold them in position in bed.

Shaped supports

Sand bags provide effective support but they should be covered with some soft material to make them feel better against the body. Otherwise the parents would like to pillows tailor-made to fit the shapes of the children with pillowcases in different colours. For example: a pillow to support a scoliosis spine when the child is lying on one side and another for the other side. Special pillows providing support to prevent them from bending dislocated hips. Giving the pillows different colours would make it easier for a sleepy parent to turn the child during the night and position the pillows correctly. Naturally the children's movements must be encouraged if they try to move in bed and the support pillows should not be used unnecessarily. But if supports are needed and such stop-gap solutions as toy animals and the suchlike are resorted to, then it would perhaps be better to have pillows that were correctly shaped to fit the child's body. It must not be forgotten that the

children cannot right themselves or move when they feel something lumpy or uncomfortable and they often have plenty of other things that can disturb their night's sleep without having to worry about lumpy pillows that have ended up in the wrong position under their bodies. In general the children, just like everybody else, need ordinary bedding consisting of sheets, pillowcases and pillows, duvettes and blankets. The bedding should be easy to wash in a machine and should tolerate frequent laundering.

Communications aids, etc., are required to keep the parents and children in touch with each other during the night. In order for a child to have his/her own bedroom and for the parents to have a bedroom of their own as well without jeopardizing the child's safety, an intercom can be set up between the child's bed and the parents' room. Only one family has such a device, and it works well. The others, with the exception of those families where the children and parents share the same bedroom, feel that it would be of great help to have a "Geva-vakt" model intercom. This model allows the line to kept open so that the sound the child makes can be heard all the time, as though one was there. The parents can hear the child's breathing and "cramp sounds", they can hear when the child cries out and when the child is sleeping soundly.

Disturbed sleep

The children will not feel afraid of being alone at night if they know that their parents will come when they "call" or cry out. This gives the children a feeling of safety and counteracts any feelings of their incompetency they may have, and it allows the parents to sleep securely - they can close their bedroom door without having to worry that anything is going to happen to their child. The present situation means that the parents cannot sleep securely. They often wake worried and go to the child's room to look in and listen for

sounds of breathing to satisfy themselves that everything is all right. Some of the children require immediate medication if they have an attack of cramp.

The parents are often afraid that they will not hear when the child has a cramp attack and will not be able to help the child then. Some of the children have severe problems linked to phlegm production that can involve breathing difficulties when the child has an infection and in such cases the child can require immediate assistance during the night in breathing and in removing the phelgm. More than half the parents therefore feel that it would be a great help to have some sort of appliance that detected the child's cramps and sounded an alarm in the parents' bedroom. The same sort of system is required for breathing difficulties. Some of the parents are afraid that they might not be woken by the child's whimpering, even with the "Gewavakt" intercom, and would like to have an alarm for this as well.

An alarm that rings a bell like an alarm clock could possibly wake up everyone in the house. Most families feel that an alarm that causes vibrations under one of the parent's pillows would work better. This would enable the child to sleep without having an

uneasy parent lying alongside or running in to check on the child during the night. The parents could then sleep in their bedroom in the normal way and would only need to be with the child, or get up to provide help, when it was really necessary - assuming that the alarm device is totally reliable. As it is at present the parents feel that they are an all too vulnerable "human factor" in the chain of responsibility of looking after the children and they need the help of technology in order to feel more secure on this point.

Phlegm formation

A vibrator might be of assistance in loosening phlegm and evacuating it easier when the children are infected and have difficulties with phlegm formation in their lungs and windpipes. Three of the families would gladly try such an aid, providing that the child's doctor and physiotherapist agree. Breathing exercises are felt to be laborious for both the child and the parent and furthermore it is difficult for untrained persons to make their hands vibrate in the same way as a physiotherapist's to properly loosen the phlegm.

None of the children can themselves put on their lights when they wake up at night. This is because a suitably adapted switch, i.e. one that is touch-activated, is not available. If such a switch, say with a diameter of around four inches which worked when it was just touched (not pressed in), could be situated at a suitable place near or in the child's bed, then possibly five of the children could then decide themselves whether they wanted darkness or light in their rooms. This would provide the children with a small degree of independence and increase their self confidence. In addition it would motivate the children to use their hands, giving as it does an immediate effect of the desired type to a "minor" movement by the child. Putting on and of the light by themselves would be a meaningful - concrete - activity for a severely mentally handicapped child.

COMMUNICATIONS AIDS

The ability to transmit information between people is naturally a major requirement for all of us in order to be able to function. Our most usual means of communicating with the people around us is through sounds, i.e. "speech". But we all use mime and body language more or less deliberately.

None of the children in the survey can "talk". Only one of the children can be shown to understand a lot of what is said around him/her. In some cases one can suspect that the child understands some spoken words, but this can be as "signals" and not as "symbols". All the children that can hear certainly recognize voices and seem to be very conscious of the atmoshpere and tone of voice around them. Miming and body language, which are often totally controlled by the emotions, are certain understood completely normally by all the children that can see or feel everything.

Comprehension difficulties

The children communicate with the people around them by using a totally personal "body language" comprising sounds consisting of types of laughter, cries, sobbing, babbling, whimpering, etc., with all their variations. One has to know the child personally very well and all his/her habits in order to work out what the child means by the "language" used. Sometimes it is diffcult even for the parents to understand their children. For instance, if the child cries out, obviously in pain, they still do not know what is causing it. The child cannot point, cannot answer in the affirmative or negative; the only way is to keep on crying out until help is provided or the child realises that the people in the vicinity understand what is the matter. Sometimes the parents have to resort to a process of elimination in order to find the cause of the problem, and this can go as far as having the child medically examined "for safety's sake".

No one has ever attempted to teach any of the children a logical body language that could be understood by others in the family. Half of the parents feel that it would be worthwhile to try and teach the children some body language signs. Two parents believe that their children could learn to point to simple, clear pictures in order to make themselves understood.

For instance a picture of a glass could be the sign for "thirsty", a picture of a diaper could mean "it's time to change me", etc. Symbols are certainly too abstract and difficult for all the children except one who understands images and speech. The parents want efforts to be made in the future to try and teach even children that are as severely handicapped as these some form of logical sign language in the training schools.

Well-known voices

We have the telephone, for example, when we want to talk to each other over a distance. None of the children can use the 'phone except for listening to. If a child calls home then he/she can hear the parents' voices but cannot communicate with them. Four of the children show clear indications that they recognize voices even on the 'phone and the parents believe that the three of these children who can see would be able to communicate using a viewphone. They would be able to "talk" to the parents over a viewphone using their "body language" and miming. If the telephone number to the mother's place of work, for instance, was preprogrammed, then the child could "'phone" by touching a large touch-activated switch and could then see Mother and "talk" to her using body language. As things are at present the children most often do not have any way at all of communicating over a long distance. They cannot write a letter themselves or record a message on a cassette and post it. Naturally someone can help them write a card or letter or record a tape and send it, but but this is an indirect form of communication that is probably not

understood by the child, but naturally can even so be greatly appreciated by the recipient.

A paging device activated by the child's special sounds can enable the parents to relax. They do not have to reamin continually within earshot of the child - they can even shut the door.

Viewphone
Paging device
Communications radio
Touch-activated switch for remote-control of TV or radio
8 mm film camera
Camera with projector for slides
Polaroid camera
Dog tag with personal information
"Mini" medical records

Insecurity at night

As the children cannot move around by themselves, they have limited possibilities of using their own way of communicating even in their closest environments. The use of body language requires that people be physically close to each other and using different variations of sounds without having to move or open doors also means that they have to be in the same room. This is a cause for considerable insecurity in both the children and parents. The night-time problems arising from the inability of the child to call for help in emergencies if he/she sleeps alone in a separate bedroom without a communications aid, have been described in the "Sleeping Aids" section. Using the technology and aids available to us "normal" people, it should possible to solve many of the substantial problems that the families have. An intercom between different rooms in the family's home is an example of one desirable aid. Six of the families would like an intercom between the child's bedroom, the parents' bedroom and the living room, for example. What is wanted is the type of intercom that can be set to listen, so that during the night sounds from the child can be heard without disturbing the child. As it is at present the majority of the families must have the doors open between rooms and often go and check on the child for safety reasons. The TV sound has to be kept low. While the TV is on one still has to be able to hear the child without disturbing his/her sleep. This means continual monitoring and worry that one will not hear the child's "cries" for help which make it diffuclu to relax even when the child is asleep. The possible use of a paging device and communications radio, adapted for the child, would increase the freedom of the child and parents by extending the means of communication further than between the rooms of their home.

The ideal aid of this type would perhaps be a combination of the two. For example, a transmitter that registers the child's personal

sounds and generates an audio alarm, vibrations or a flashing light in a small receiver that the parents could carry in their pockets, for example, when the child cries out. It should also be possible for the parents to set their receivers so that they could listen to the sounds the child was making and hear what type of "cry" it was. There should also be the capability of transmitting from the receiver and talking to the child through it. In other words the transmitter/receiver would act both as a paging device and a communications radio between the child and the parents without the child having to press any buttons or the suchlike. If this "perfect" apparatus could also register cramps and trigger an alarm it would provide another important function for several of the familes. The transmitter and the receiever could be battery-powered so freeing both the child and the parents from dependence on mains electrical supply.

Out of earshot but within reach

Several of the familes know of a paging device that is activated by the sounds emitted by a specific child that was manufactured as a prototype by Gewa and they hope that this type of aid for people that need to be able to summon assistance rapidly without pressing buttons will soon become generally available. This would give the families a greater degree of freedom than at present. As it is the parents cannot both leave the child and go out into the garden. Someone has to continually be within earshot of the child. With the communications aid described above the parents could safely leave the child and move around within an area which would allow them to rapidly reach the child and provide assistance when required. A neighbour could "baby-sit" in his/her own home using the device to make sure that the chid was safe while the parents went shopping. It would be possible for the parents to take a short evening walk while the child slept. The child could safely remain in the car while the parents carried out essential errands, e.g. in the post office, shops or other places inaccessible to wheelchairs. This

Would mean a little normal freedom for the family. For the handicapped children, particularly teenagers, it would give them the chance to feel independent and be "left alone" in a way that is normal for their age.

Other teenage children often have a compelling need to go into their rooms, shut the door and get away from their parents for a while. These severely handicapped children and young people have emotional needs corresponding to their ages and it is probably a very great mental strain to always have someone looking after you when you are at an age when you want to "do your own thing". This is a continual reminder to the children of their helplessness and inablity to manage to do anything on their own. If the children learn to use a communications aid of the paging/communications radio type then they can hopefully feel independent and secure.

Different sounds - happy, sad

A further example of an area of application for this type of aid: If the family goes on holiday and lodges in a hotel or similar then the parents can leave the child in bed or alone in the room while they go and have dinner in the dining room, go for a walk and socialize with other patrons or drop in on the "night club". When the child needs help or wants the parents to come, he/she "calls" and the paging device generates a signal, preferably a "vibrator" in the parent's pocket. The parents then go immediately to the child or go to one side and listen on the communications radio to the type of sound the child is making. Perhaps "happy" sounds or laughter have activated the paging device, and there is no reason to rush up and provide assistance. If the sonds are "unhappy" the parents can "talk" to the child over the radio and say that they are on their way.

If the sound is of a cramp attack or a cry of panic, then the parents must rush up and provide help. It should also be possible to use the apparatus when visiting hospitals, for example. The other hospital patients can always summon a nurse by pressing a button and people who cannot press buttons, like these ten children, do not have that capability. If the child is in a separate room in the hospital - the doors are shut and the child's cries are not heard - then someone has to continually sit with the child to be able to provide assistance when required. This is one of the reasons why the parents most usually accompany their children when they are in hospital. Otherwise the child needs extra staff just to "watch" him/her.

Naturally communications aids can never replace the people one associates with. They cannot replace the parents or other people.

TV and radio

TV and radio can be mentioned as among the other aids that in the widest sense can be reckoned as aids for communications between people in our society. Six of the children get a lot of pleasure out of looking at colour TV. One of the children, who is less severely handicapped that the others, certainly recognizes people on the TV screen and understands what is said when, for instance, someone reads stories in the children's programmes. The other five enjoy and are interested in looking at TV, even though one cannot know what they understand from the images. Several of them recognize some programme theme tunes and have their "favourite" programmes. All of the children are totally dependent on other people turning the set on and off for them. They cannot make themselves understood to the extent that they can say when they want to look at TV and what they want to see. A step towards rectifying this situation would be to equipped the families' TV sets with a large touch-activated switch

with which the children could remotely-control the TV. Contact with the switch would enable the child to turn the TV on or off. Possibly there could be switches of different colours for the different channels so giving the children the same choice of programme as everybody else has.

Several of the children often listen to radio programmes and recognize the signature tunes of their favourite programmes, for example. The radio sets should also be adapted using sizeable touch-activated switches so that the child could turn the radio off and on and select different programmes. As several of the severely visually handicapped children get a lot of pleasure from the radio, but cannot see differently coloured buttons to select the programmes, the switches should not just have different colours but should be differently shaped as well so that they can be differentiated by feel.

Tape recording

All but one of the children have good hearing. In addition to the radio they like listening to cassette tape recorders. Nine of the parents feel that their children have a need of a cassette tape recorder as an aid. Six of them have tape recorders and use them often. Over and above listening to tapes of music and stories, they can record and listen to the voices of people around them, they can record various well-known sounds, etc. Using the recorder the child can retain a sound experience and then tell other people about it by playing back the tape. For example, record a tape together with the class at school which the child can listen to at home with the parents and in this way "tell" them about what happened at school. In the same way the child can record a sound from the home and "tell" about it at school. In other words the tape recorder can be used to communicate with even if one cannot speak or understand words in a spoken language. The children's tape recorders also need to be equipped with large touch-activated buttons so that they can turn them off and on themselves.

The parents believe that over half the children could learn to turn such appliances off and on with a large touch-activated switch when they wanted.

8 mm film camera

There are other aids than tape recorders which can be used to communicate and remember with that several families feel would be of great value for their children.

Perhaps an attempt could be made with an 8 mm camera to film family events so that the child could subsequently be able to "remember" and "tell" other people about it by looking at the films. It is uncertain how the children feel about photographs and films. None of the parents of the severely handicapped children know if the the children "recognize" photographs or pictures. But several of the children get a lot of pleasure from and are very interested in looking at photographs.

Four of the parents would like to have a camera and a slide projector so that they could take pictures of the daily life of the family and the child and then look at them with the child and try to get him/her to understand that they are a representation of reality. What is wanted is a Polaroid camera, which produces a print right away, so that the child could photograph a situation which he/she experiences as reality and then immediately afterwards see the photo and compare it with reality.

The parents also feel that this is something that is an ideal training experiment and training school activitiy. Naturally none of the children can communicate by writing or use writing aids. One of the children is pleased if someone reads out loud, the others certainly do not understand the actual words in a "story", but can anyway enjoy listening to the voices in nursery stories.

We use notes and "records" as communication and memory aids in many applications in the society in which we live. We have identification documents such as social security cards or passports. If any of these ten children "get lost" or are left alone because something happens to the person who is looking after them, then they have no chance of making themselves understood whatsoever.

Who am I?

The majority of the parents feel that everybody who cannot speak should carry an "SOS talisman", i.e. a dog tag that can be bought at the chemist's containing information on name, address, telephone nos. of the child's parents and doctor, epilepsy medication used, the nature of the handicap, etc. Several of the children are driven to school unattended in a taxi, and should anything happen then they would be helpless. If there were a traffic accident then people might not understand that the child was severely handicapped, but suspect that he/she was suffering from shock and provide the wrong treatment. According to one of the parents, single parents with severely handicapped children of this type should also carry an SOS talisman which would request that contact immediately be made with a certain person or emergency service concerning the child should the parent be involved in an accident. Otherwise the child could be left unattended while the parent was lying unconscious in hospital.

When the family goes on holiday, at home or abroad, it should be possible to take some medical notes in summary form, possibly in English, from the rehabilitation authorities. Often the child's own doctor cannot be reached rapidly in an emergency and if the family is in another part of the country or overseas then the child's medical notes would not be readily available. When the

family, for example when the child is experiencing an attack of cramps or is suffering from infection, visits a doctor who has never seen the child before, it would be a great help to have some documentation of the child's disability, medication, advice for acute cramps, etc., from the child's ordinary doctor.

SITTING AIDS

As mentioned in the beginning of this report, none of the children can control the trunks of their bodies, i.e. can hold their trunks upright without support. Six of them cannot hold their heads up either without support. Seven of the children have scoliosis, which is an abnormal curvature of the spine laterally. In some of them the scoliosis has caused substantial deformations of their spines. Three of them have hip joint luxation. Six are spastic and subject to involuntary movement and muscular spasm.

These difficulties make it impossible for the child to use our ordinary sitting aids, i.e. "chairs", without them being specially adapted. The availability of aids to allow one to sit comfortably and "correctly" in different situations is even more important for people who cannot by themselves hold their bodies in these positions than for us "normal" humans. This is not just important so that the child can sit comfortably, but also to prevent a deterioration in the child's condition, e.g. through the occurrence or worsening of scoliosis, the dislocation of the hip joints or the inception and worsening of contractions.

Some of the children only have one indoor sitting aid - a wheelchair - and the majority have two, i.e. an "armchair" in addition to the wheelchair. For these children these aids have to perform all the functions of all our types of chairs and sofas. Furthermore they have work in those situations where other children "sit" without help, e.g. when playing on the floor, on the ground, in the sand pit, etc.

Seating furniture

Examples of different seating furniture that we ordinary people can use on various occasions in our lives are: chairs of the correct height for the dining table; stools of a height suitable for the work surfaces in the kitchen; chairs for writing desks that can have their height adjusted, can be swivelled and are mounted on castors; chairs for watching TV possibly with footrests and with arms and headrests, that can be tilted backwards and swivelled; three-piece suites round a coffee table; garden furniture that can be folded up and sun lounger beds.

All the children have to have some form of wheelchair indoors. The three youngest children use "Flexi" or "Ortho" wheelchairs. Two of these require specially adpated backrests so that the child can sit comfortably and in one case this has been satisfactorily solved by using a piece of foam plastic to counteract the effects of scoliosis. The other child who needs a special backrest sits uncomfortably and can fall out of one side of the chair when body movement is violent. This child needs better support for the whole trunk and the edges and corners of the wheelchair should be covered in a soft, protective material.

The "Flexi" and "Ortho" chairs are felt to be easily manoeuvrable indoors and their height can be altered. They are also possible to tilt backwards. The parents feel they work quite well. These children are still so small that they usually sit on their parents' knees when it is not practical for them to sit in the wheelchairs.

If the "Flexi" or "Ortho" wheelchairs are to accompany the child on a car trip they have to disassembled, which is possible, with some difficulty. The chairs take up a lot of space in the cars and it is felt that it is difficult to take other luggage if the chair is included. On visits the guests do not want to take a dirty

wheelchair into a house, but prefer to leave the chair outside and carry in the child who lies in a bed or on a blanket on the floor during the visit. The wish was expressed that the wheelchairs be designed so that they could be taken apart (like the "Tore" chair) so that the seat could be removed from the chassis and used as a car seat or be put on an ordinary sofa or armchair.

Uncomfortable sitting position in wheelchair

Of the seven older children, six have "Hantverk"-design wheelchairs. They all have scoliosis and hip joint problems. Three of these children have "Hantverk" chairs without any modifications and sit very uncomfortably in them. One of the children therefore almost never sits in the wheelchair, but spends most of the time lying down because she does not have a specially-adapted chair in which to sit. The other children do not use their wheelchairs outside or on the school bus because, among other things, they do not have headrests and cannot therefore be tilted backwards when required. One of the children who travels daily to school sitting in an unmodified "Hantverk" chair often cries with pain when she sits in the chair. A customized backrest has been ordered for this child's chair.

Three of the children have "Hantverk" chairs which specially-shaped backrests with shoulder supports. The children sit in these chairs rather well and the parents feel that there is a considerable improvement over how they sat before. But the children do not have the stamina to sit in these chairs for long periods. The shoulder supports are hard and leave pressure marks and they prevent the circulation of blood in the arms. One of the children is very prone to "blue" arms and hands when sitting in the chair. Efforts have been made at placing foam plastic cushions over the shoulder supports and using pile cushions in the chairs, but these unattached articles often end up in the wrong position and are

difficult to use so that the child is really comfortable. The shoulder supports can be adjusted laterally but have "sharp" fittings that people often come into contact with. The height of these supports cannot be altered with the result that they often end up too high under the arms when the backrest is tilted backwards.

One child has a "Kifa Postura" wheelchair and some of the children have an old "Kifa" wheelchair as a spare. This child does not have scoliosis but is severely spastic. This child only requires minimal support at the sides to hold the back and feels that the "Kifa" chair works well to sit in.

All the children have great need of soft, firm supports for the entire trunks of their bodies in order to be able to sit comfortably and still have some freedom of movement. They require customized backrests with shoulder supports that are vertically and laterally adjustable. It should be possible to angle the seat if required.

Improved wheelchairs

All the parents of these older children would like a better designed wheelchair which would enable the children to participate in normal social activities in an entirely different way than at present.

The "Hantverk" chair has a large turning circle and is unsteady when in motion. Therefore there are only certain places in the home where there is room to use it. The children always are restricted to "their" places in the home and have no chance of obtaining a concept of space. The wheelchair has to be turned round and reversed over an ordinary threshold in order to negotiate it, and this is a lot of trouble and requires room to turn.

This wheelchair has many sharp parts that mark doors, walls and furniture and, not least, the legs of other family members. This cannot be avoided because the wheelchair is so difficult to steer that it often takes more room to manoeuvre than one believes.

The "Hantverk" wheelchair has a good seat that is easily angled. The backrest is infinitely adjustable a bit backwards on both this model and the "Kifa Postura", but not sufficient to adopt a fully supine position.

This is inadequate because in some situations the children need to be able to stretch out full length in the wheelchair. Perhaps to rest or sleep after a bad attack of cramp. Away from home, e.g. when out in the town, it is very difficult to change the child's diapers if the wheelchair cannot be set in a level position. One of the children has a ruptured oesophagus and often needs to lie face down to aviod pain and the present design of the wheelchair prohibits long periods away from home. If it were possible to put it into a flat position then the child could lie face down in the chair and rest for a while even during a trip away from home. As things are at present, this family and several of the others seldom travel away from home just for this reason.

Head support necessary

All the children need a back support that can be tilted backwards because they often need to change their sitting positions and rest their backs. All the children require a head support on their wheelchairs. This is necessary to allow even those who have control over their neck muscles to rest reclining in the wheelchair. Several of the children need a specially-shaped head support which counteracts their erroneous reflex actions. It should be possible to set the head rest using a simple but safe mechanism to adjust its height, move it forward or backward and angle it, which in some cases can be necessary, e.g. when feeding the child. Three of the children have no head supports on their wheelchairs.

It must be possible to adjust the height of the wheelchair if it is to be able to replace, for example, a dining table chair, a TV viewing chair, and if it is to function ergonomically in personal hygiene situations, when feeding the child and for hoisting the child in and out, if it is to act as a sun lounger bed at the beach and in situations with other children who are perhaps playing on the floor. None of the seven older children have this capability, and this severely limits the parameters of their world. In social terms they are pushed to one side when there is not room for the wheelchair.

Flat chairs

Often the children have to be both dressed and undressed on the wheelchair, and this presents particular difficulties with a spastic child who lacks trunk stability. It would be a great help if the wheelchair could be tilted backwards into a flat position and if its height could be adjusted to a suitable working position. It would also be easier to lift the child in and out of the wheelchair, which is sometimes unavoidable, if its height could be varied. The wheelchair should also have side supports that can easily be removed and the height adjustment mechanism should be easy to use. The absolute ideal solution would be if it were possible to position the chair entirely flat and then lower it right down to floor level (perhaps with wheels?) so that the child could be slid onto the chair from the floor or ground. It is very difficult for the parents to lift the children up alone on to the wheelchair from the beach, lawn, gymnastic mat or other place which is at a lower level. At present two people are required to lift the bigger children into and out of the wheelchairs without a special lifting aid, unless one wants to run the risk of pulled back. Some of the parents pointed out that the seat should swivel like an office chair so the children could look around them without having to turn the entire chair. This would give the child greater freedom in the room. When something interesting happens behind

them they could easily spin round to see what was going on. One possibility is that all wheels would be lockable castors.

Often the children have to be both dressed and undressed on the wheelchair, and this would be made very much easier if it were possible to tilt it backwards into a flat position and to adjust the height to a comfortable working position. It would also be easier to manually lift the child into and out of the wheelchair if its height could be varied.

In order to permit the children to reach, for instance, kitchen work surfaces, cupboards, wash basins, etc., it should be possible to turn the wheelchair round and have the child kneeling on the seat with the chest against the backrest which should reach up to the armpits. The child would therefore be hanging over the tilted backrest with the arms free behind the wheelchair to work with. It is certain that several of the children could use this method. Possibly an extra support would be required as an unattached accessory for the wheelchair to hold the child's back in place, preventing it sliding to one side. One of the younger children's parents uses this method of "raising" the child by getting the child to kneel on the wheelchair instead of having a tipping board at home.

The function of the table

Nine of the children require tables for their wheelchairs. Several of the children can support themselves using their arms by leaning against a table that is mounted on the wheelchair. It is necessary to have the children's food on a wheelchair table because the design of the "Hantverk" wheelchair prevents it being positioned under the dining table. When the child is to be fed outside the home, a table is required on the wheelchair in order to be able to hold the food and feed the child at the same time. A table is required when the child is going to play with things to keep them close enough.

Five of the children have wheelchair tables. Four of them are very displeased with their design and function. The fifth family has made a wooden table themselves with edges that is customized for their young child. The "Hantverk" design of table seems to work very badly. It is made of wood which chips off at the edges and is joined together with ordinary staples. It is impossible to keep the joints and cracks clean. Moreover, both this model and the "Kifa" table are too narrow for the children to rest their

arms on with their arms positioned at their sides without hurting themselves on the edges.

It is difficult for the children to "play" on this table, and the parents have completely different ideas of how the table should meet the children's requirements. The table should be shaped round the child so that the arms can rest on the table at the side of the body when desired. It should be easy to install and remove, and it should be possible to alter so that it remains in a constant position in relation to the child without tilting backwards when the wheelchair's backrest is inclined backwards. There should also be the capability of angling it so that, for instance, books, illustrations, toys, etc., can be leant against it enabling the child to see and reach them even when sitting leaning backwards. The material must be very easy to keep clean (perhaps Formica?) and should be provided with raised edges without joints into which liquids can run.

Table top insert

Many of the children experience difficulty in bending their wrists and getting their hands over a lip. If a bowl or a box is put on the table the children therefore have great difficulty in reaching down and touching it. This would be made easier if an idea that one of the parents had, and which the others when asked thought was very good, could be implemented. A large round hole could be cut in the table - the disc could be reinserted so that the table became "whole" again. A bucket full of e.g. water, sand or other material that the child needed to "get to know" could be put in the table top insert. In this way the children would be able to obtain better access with their hands as there would not be any high edges in the way and the bucket could not be knocked over by any of the children's abrupt, uncontrolled movements. Even "take out" and "put in" games, necessary for the children's experience of the things that surround them, would be facilitiated by such

a table allowing, as it does, things to be put into a bowl-shaped recession in the table top.

If it were possible to take the wheelchair apart so that the seat could be separated from the chassis, then the "seating section" could be used as a car chair to put on an ordinary car seat. This would give the older children the chance of sitting in the front of an ordinary passenger car with the seat belt on in the normal way. The problem would be getting the child into the car because both the child and the wheelchair seat would have to be lifted in and out at one and the same time. Otherwise the child has to be laid somewhere while the seat is put into the car first. The same problem arises when leaving the car. If one had two wheelchairs modified for this purpose then the problem could be solved by having two seats and one undercarriage when making trips by car.

The need of stimulation

Even if the children were to have their sitting aid requirements met, as varied as described here, they still need several different things to sit on. Eight of the parents feel that their children need a customized foam plastic armchair to sit on when watching TV, for instance. Six of these children already possess such a chair, individually shaped. Some of the parents are very pleased with these chairs, because they are the only chairs in which the children can sit compfortably with a soft support for their scoliosis. One of the children receives far more stimulation to move in the soft armchair than otherwise is the case and therefore experiences new sensations of being able to lean over and rock backwards and forwards without danger. Some of the children have grown out of their armchairs and can no longer sit comfortably in them and they are waiting for them to be re-shaped. In one case the chair was completely wrongly put together from the beginning - there was no support at the sides - so that the child fell out and consequently does not like to sit in it at all.

Sitting in such an armchair the children can, like others, have their feet on the floor and feel different floors, carpets, etc., with their feet. This is important because feet are sensitive parts of the body for the reception of sensory information from the outside world and the children need a lot of sensory impressions and experiences of their surroundings. If the armchair were mounted on small wheels then the children could perhaps propel themselves round the room by kicking. None of the children have had the chance to try this, but the parents are interested.

It would also be possible to make a swing scaffold and suspend the foam plastic armchair on it so that the child could swing by kicking and learn to move the body to gain speed. If they cannot swing themselves they could anyway have someone swing them in the chair. All children like to ride a swing. It is very difficult to find ways of allowing the children to activate themselves. All the families with the exception of one feel that having the child swinging in a chair would be a very good activity. It was also felt that the children should have this opportunity at school. The swing scaffolding, on which the foam plastic armchair would be placed, should be collapsible in order for it to take up only a small amount of room when not in use.

Sagbags

Another type of chair that six of the families could use for their children is a sagbag, a canvas bag filled with tiny, polystyrene granules which adapt naturally to the shape of the body, covered with an airy textile that is not too hot to sit or lie against. The plastic granules follow the shape of the children's bodies when they move while supporting them fully and the children can feel and hear how they granules move inside the bag. Normal children like to wrestle and jump on sagbags which are generally available in furniture stores in different shapes and sizes. The parents feel

that this aid could stimulate, for example, the deaf/blind children to move and activate themselves through their sensory impressions.

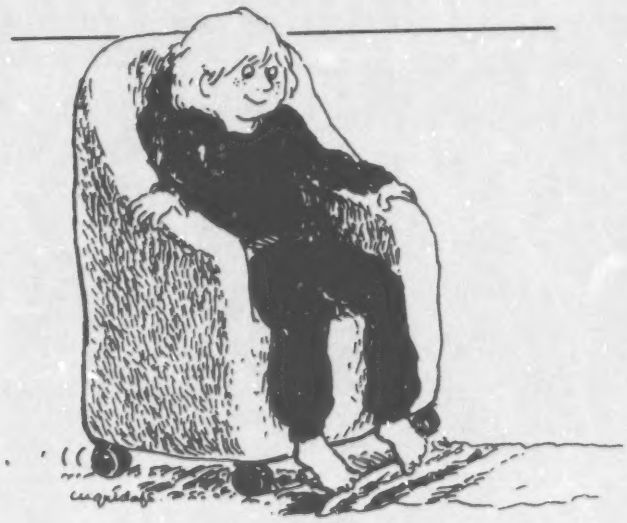
One of the familes does have a sagbag for their child and it is the only chair the child can sit in. She sits in it when she is being fed - the only alternative is her mother's knee, although she is a teenager. She also uses it when lying on her stomach and straightening her spine. In this way she can, as far as her severe scoliosis allows, adopt a crawling position and use her arms and knees to support herself.

Eight of the families - all with the exception of those with the two youngest children who still sit on their parents' knees - have a great need of sitting aids for their children that can be of a suitable weight and volume to permit them to be easily transported. Something which takes up very little space in the car, which in addition to the wheelchair has to carry all the rest of the family's luggage when going on a trip.

Together in the countryside

Several of the parents believe that this type of sitting aid would give the whole family a good few opportunities of going out together. It would be less trouble - perhaps one would be able to visit friends more often. It would be possible to take the child out on boat trips, trips into the countryside, etc., which are most often avoided because there is not room in the boat for the wheelchair. If the family is going on holiday then one has to decide whether to take the wheelchair or the foam plastic armchair in the car. Several of the families choose the armchair because the child sits in it better, but then they have no means of transporting the child during the holiday.

Knock-down wheelchair
Supports
Collapsible wheelchair
Vetically adjustable wheelchair
Swivelling wheelchair
Table
Wheels under foam plastic armchairs
Swing scaffolding
Sagbag
Lightweight, easily transportable chairs



Some of the children could kick themselves round the room if there were wheels on a customized foam plastic armchair.

MOBILITY AIDS

None of the children can move around in the natural way, i.e. by walking. All of them need a wheelchair for indoor and outdoor use. None of the children can operate a manual wheelchair by themselves and none of the children have tried to learn to use an electric wheelchair. In other words all the children require a human aid to enable to move around using the technical aids.

This is true both for moving around in their immediate surroundings, e.g. indoors, and for longer trips.

In order to move around indoors a wheelchair that is of a completely different design to that which at least the older children have, which was described in the Sitting Aids section, is required. Those children, just the same as the rest of us, need to have access, particularly in the home, and have to be able to turn in all directions in order to be able to reach things and be included in social activities and see what is going on.

The wheelchairs should be equipped with shock-absorbers on their periphery so that damage to the homes of families with children in wheelchairs is avoided. As it is at present there are unavoidable scratches and scrapes on walls and doors left by the wheelchairs' hub caps, footrests, bolts and sharp, protruding parts. This is a problem for most of the families with the result that in the home one avoids positioning the wheelchair in areas where space is tight or near expensive or vulnerable furniture, which disregards the wishes of the handicapped child.

Independence

If the children had the possibility of moving themselves using their aids they would have the chance of obtaining a normal concept of space and distance determination, a modicum of independence, self

confidence and experience that they would presumably never get by always being moved around by another person. As the children cannot make clear where they want to be moved to, they do not often get to do what they want and have the chance to develop their initiative. They become passive because they perhaps do not understand that they could influence events themselves. They only display pleasure or disapproval at being in a situation, not because they want to try and change that situation to another.

Electrical wheelchairs

The parents are very interested in electrical wheelchairs, for instance, but they are very uncertain as whether their children could manage to learn to move themselves around using such a device. The one child who is not so severely mentally retarded as the others could probably learn to operate an electrical wheelchair if it were modified so that the child could operate it by inclining his/her head in different directions. One of the other children could perhaps learn to operate a traditional electrical wheelchair if the control knob was customized into a large knob positioned in front of the child - this family is very interested in giving the child a chance to learn. Several of the other children are so visually impaired that the parents feel that they could not manage operating a complicated electrical wheelchair even if it were fitted with signals and a guidance system, etc. However, three of these parents would like to let their child try, if they had the chance, to operate an electrical wheelchair at home. This would have to be fully pre-programmed to run on a certain route or follow electrical loops laid in the floor. The child would then only have to start and stop the chair.

Under such circumstances even visually impaired children would be able to move towards voices or recognized sounds so enabling them to join other family members if they wanted to, providing they could learn to stop the wheelchair when they wanted at the desired place.

According to the parents, therefore, half of the children in the best case could learn to move around the home with a properly modified electrical wheelchair. As the parents have never previously considered that it could ever be possible to produce an electrical wheelchair customized to the extent that even their severely handicapped children could attempt to use this type of aid, such thoughts were entirely foreign to them. It seemed as though they did not dare to use their imaginations so as not to make unrealistic expectations of the children. But neither did they want to rule out the chance of this being possible.

Naturally patience, time and training are required if the children are to make what is for them important progress, but it does not have to be impossible. The opposite has yet to be proved.

Specially-made overalls

When young, several of the children were able to move around a little by kicking and sliding over the floor surface, by kicking themselves around in a baby walker or by jumping about in a baby bouncer. Now that they have grown they cannot manage this and only one of the children has an aid that functions for this purpose. One child has a harness on the ceiling hoist so that the child can walk along a ceiling-mounted track suspended in the harness. This harness is specially made as an overall of parachute cloth and is fully capable of withstanding the large loads it is subjected to. The boy is big and tall, severely spastic and visually impaired. When he walks in his overall, suspended from the hoist, he looks very happy and marches proudly backwards and forwards along the length of track despite severe contractions in his legs and arched feet. It is very good training for him to make the physical effort he wants, and he seems to feel that this is very meaningful.

Two of the other older children were previously able to stand on their legs and one of the children had a functioning walker when he/she was younger which was used to develop the strength of the

legs by activities performed alone. There is presently no walker that is sufficiently strong to hold the child's large, unstable body. One of the younger children loves to walk when the parents hold him, and he could certainly learn to move around using a baby walker if he were given one that could support his entire trunk.

The children need aids that enable them to move around under their own power. They need to be given the opportunity of driving individually customized electrical wheelchairs. One of the children requires a traditional electrical wheelchair with modified controls, some of the others perhaps need a traditional electrical wheelchair with shock absorbers round it designed not only to protect the surroundings but to stop when impacting on something. This would allow the child to learn to use the wheelchair in the security of the home without damaging it, even if this took several years, thereby affording the child an instructive occupation insomuch as the wheelchair would enable the surroundings to be explored.

Perhaps smaller chairs, that do not take up so much room, like office chairs, could be modified to allow the children to move around in them by kicking.

"Skateboards"

Modified "skateboards" enabling the children to lie on their stomachs and move forward by kicking have not been tested at all, but could perhaps be worth a try with some of the children.

In order to be able to move around outdoors, when we other people walk, cycle or jog, etc., the children need a functioning aid to give them the same opportunities. None of the parents feel that their children have the ability to learn to move around outdoors themselves with, for example, an electric wheelchair. They always need a human aid to operate the technical aids.

Wheelchairs outdoors

The most important mobility aid outdoors is the "wheelchair". Two of the three youngest children have a "Mini-max sulky" which is modelled on the carriage that the jockey sits on behind a trotting horse, and they are more or less satisfied with this. These children do not have scoliosis and they can sit in the chair leaning slightly backwards without any special modification being necessary. The parents feel that the "sulky" works well. One of them has replaced the wheels with the "Max sulky" wheels which give the child a better ride. The third family with a young child uses the "Thore" chair as an outdoor chair. It is works well outdoors, is easy to dismantle and carry in the taxi to school, but the child, who has scoliosis, sits very uncomfortably in it. The parents wish that it were adapted to suit the child's back so that it felt comfortable. As things are are at present, they know that the child feels discomfort after sitting in this chair for long periods. The result is that they do not go out with the child as often as they otherwise would. The medium-sized children have only used the "Max sulky" and the parents think that they are quite easy to use outdoors. However, as the children have scoliosis they have never sat comfortably in the sulky despite being supported by cushions and pillows, and the carriage being modified so that the backrest inclined more than on the standard model.

These children and their families are now trying to get used to using ordinary wheelchairs outside as well, instead of the "sulky" carriages, because they have outgrown them. All of these children have "Hantverk" designed wheelchairs with the exception of one who has a "Kifa Postura". The "sulky" carriage allowed small obstacles, kerb stones, etc., to be easily negotiated and it was a simple matter to fold the carriage up. Moving about outdoors with the wheelchair was a terrible disappointment. All the families have had their life styles limited by having to change over to a wheelchair. It is no longer possible to travel in an ordinary passenger car with the child and the

wheelchair. It is not possible to go round the town without reversing over every kerb - this is something that the staff at one child's school refuse to do because they feel that crossing a street in this way is dangerous and if the child comes to school in a "Hantverk" wheelchair then he/she is not permitted to go out on walks.

Special chassis

One child has a special "Hantverk" wheelchair for outdoor use, which has a specially-made chassis with four non-swivelling wheels. Having been modified on several occasions it runs quite well as the child is still not so heavy that it is difficult to steer by tipping up the chair. There have been other difficulties with this wheelchair.

The wheelchair tipped over when the backrest was inclined backwards. After modification it was put into use again and a structural stay in the chassis suddenly broke clean off and the chair fell to pieces. Once this had been fixed the customized backrest soon became too small and this meant more time waiting for modifications by the manufacturer.

Three of the other medium-sized children still sometimes use the "Max sulky" because the parents and the school staff do not think that the "Hantverk" wheelchair is suitable for use outdoors. These families are extremely concerned about how things will be in the future. They already have guilty consciences because they sometimes use the "sulky" carriage knowing that their children's backs suffer from sitting hunched up and twisted in the small carriage. But how do the families otherwise get to use their cars? It is not possible to fold up the "Hantverk" wheelchair sufficiently small to fit it into the boot or luggage compartment of an ordinary passenger car. How can one go into town and shop using the family's car or a taxi? How can one solve the problem of snow-covered winter roads?

Families encounter a sea of troubles in transporting their children outdoors once they have outgrown the "Max sulky" carriage because there is no other form of wheelchair to replace this with except the "Hantverk" or "Kifa Postura" models. One single parent who previously used to take the child to the week-end cottage or winter sports centres in the car now has to use the transport service for the handicapped for these trips because the wheelchair cannot be folded up.

Several of the families have bitter experiences of the unpunctuality of the transport service for the handicapped. There is then the risk of standing waiting with a crying child, diapers soaked with urine, who could be sujected to cramps, in unsuitable surroundings.

Shock absorbers
Walkers
Various types of chassis
Remote controls
Subsidized cars
Modified electrical wheelchairs
Modified "skateboards"
Hand brake
Cross-country aids
Seats for different means of transport

In sailboats and forests

Some of the families do not take the wheelchairs with them at all when they travel away from home, but have the child lying down in the car and then lying down inside at their destination together with one of the parents.

This transportation problem means that the families cannot be together as they were previously and cannot continue with their normal recreational activities. They become abnormally tied to their homes. And if one tempts fate and goes out for a walk in rough terrain with these wheelchairs, then one puts one's physical capabilities at risk. It is hard work to push a wheelchair up the slightest incline, and often even worse to get down the other side. All the wheelchairs with the exception of the "Kifa" model lack hand brakes. When going downhill the person pushing the wheelchair has to hold it using their own strength, and this is dangerous and takes a lot out of one. In one of the families the mother is no longer capable of taking her child with her when she goes shopping in the neighbourhood because the child has a "Hantverk" chair and there is a gradient between their home and the shops.

The child who has a "Kifa" wheelchair has a hand brake. Unfortunately it is positioned so that the backrest cannot be inclined backwards sufficiently far. It also has sharp sections that stick out from the side of the wheelchair and which scratch walls, doors, furniture and other people's legs. Most of the parents who have children with wheelchairs feel that all wheelchairs for outdoor use should be equipped with handbrakes for safety reasons.

Home-made safety belt

When one of the mothers goes out for a walk with her child and comes to a downhill gradient she ties herself to the wheelchair using the belt of her coat. Should she slip and loose her grip of the chair then the weight of her body will stop it running uncontrolled down the slope.

In order to solve the problems associated with mobility the families would like to have several different models of chassis for one operational seat/superstructure, several of which would be available so allowing the child to be moved between them. An indoor chassis with all wheels swivelling, that took up as little space as possible. An outdoor chasis that can easily be wheeled over uneven terrain and which can negotiate ruts and kerbs. Either this chassis, or another one for outdoor use, should be provided with electrical propulsion enabling the attendants to control and steer the chair from a control panel positioned for their use. This electrical wheelchair should also be able to travel over grass and uneven surfaces such as paths in the woods, up steep inclines and along snow-covered roads. All the families of the seven older children require electrical wheelchairs with attendant controls in order to be able to go outside in a better way than at present. If they had the type of electrical wheelchair that is currently commonplace, then two of the families would have difficulties in finding the room to put it when it was to be charged when not in use. They live in a block of flats. One suggestion is to hire a garage in the area to keep the wheelchair in.

If there was a way to simply lift the accumulators out of the chassis and put them on charge and then fold up the rest of the chassis, then storage would not be a problem in the homes. Moreover, transporting the wheelchair would also be considerably simplified. Naturally the seat section of the outdoor wheelchair must also have a customized backrest and seat so that the child can sit comfortably. It should be possible to lower them so that the seat section becomes level with the backrest. See the indoor wheelchair section. It should also be vertically adjustable so that working with the child, lifting, etc., is facilitated.

Want to look at each other

None of these children is capable of walking beside the person wheeling the chair, because the operating lever is positioned behind the child. None of them can see the attendant, who is walking behind. The headrest on the chair and the inability to rotate the body effectively prevent communication in this way. Several of the parents feel that it is annoying not to be able to have normal contact with the child when out on a walk. As things are, one has to stop for the parents to walk to the front and talk to the child now and then. Otherwise the children would have no idea who was out walking with them.

Some of the parents would like a return to the capability of walking along facing the child that they had in the past. If the seat on the wheelchair could be rotated then this would be possible. The disadvantage would be that it would be unusual for the child to be pushed along backwards, but the parents feel that this would be offset by the enjoyment that could be obtained during the walk.

One of the parents would like the capability of walking alongside the child in a normal way when they are out for a walk. It should be possible to operate an electrical wheelchair from the side as well, and this would satisfy that wish. We have also discussed if there was a need for the remote control of wheelchairs. One of the parents mentioned that she had seen a large excavator operated remotely from a control room. Would it not be possible to manoeuvre the child's wheelchair from a hand-held control box without having to walk behind or close beside the chair?

No electricity in the summer

There should be more and better equipment available than "sulky" carriages and wheelchairs in order for the families to be able to go out into the countryside together. One of the families who spends the summer on an island without electricity or made-up roads experiences

considerable difficulties even with the "sulky" carriage, that they can still use. They have thought about building a sort of wheel-barrow that they could use to negotiate narrow paths and uneven terrain. All the families need aids for rough terrain.

We all need to be able move over longer distances - some of us regularly and daily and others only occasionally. But society is constructed so that we will be provided with functioning transport systems. It is necessary that it be possible to use these systems for these families as well. If required one can still take the youngest children, who have the "sulky" carriage, in one's arms and carry him/her onto a bus, underground or train. The carriage can be folded up and also taken along if there are some people to help. However, it is very laborious even for these families to use public transport because they often have to take along a lot of luggage and several aids with them. One example of the problem is the family who have to use a steam boat and a smaller "taxi" boat to get out to their summer island. The child cannot sit in the carriage during the journey, but has to spend the entire trip on the parents' knee. The child is very spastic and undergoes strong spasms and involuntary movement the whole time. Will the family no longer be able to go to the island in the summer, but be forced to stay in town - or must the child alone be deprived of the joys of a summer in the country and be lodged in an institution instead? None of the other families use public transport with their children any more. They have cars of their own or use vehicles provided by the transport services for the handicapped.

The need of a car

All the families, with the exception of one, feel that they have a great need of a car of their own. The family that does not feel it has the need of a car nowadays seldom travels away from home with the child, either to visit friends or go on holiday. Instead the child is periodically lodged for short periods in a nursing home,

enabling the rest of the family to go away. Of the nine families who feel that they need a car, there are two that do not own one. In one case the family, for the sake of the child, have bought a house that is so expensive that they cannot afford a car. There is nobody in the second family that can drive and the mother has not yet had the opportunity to take lessons as planned due to a lack of child minders at suitable times. They plan to get a car in the future to obtain the freedom it gives. But this family would not buy a car if their child were not handicapped.

The seven families that have cars have all changed to larger or different models in order to deal with the situation involving their handicapped child. Five of them have bought Volvo 145 estate cars which have enough room to carry a "Hantverk" wheelchair in an emergency. One of the families has also bought a trailer to hitch to the Volvo to carry all the necessary aids when they go on holiday.

One family with a young child has changed to a larger passenger car. Another has changed their small model Volkswagen to a "Passat" (hatchback) in order to be able to travel with their handicapped child. Now the "Hantverk" wheelchair does not fit in this and they have to go by coach or inter-city bus if the child is to travel, which has kept the family at home more than before. The small or medium-sized children lie down in the car or sit on their parents' laps while on the road. One of the younger children sometimes sits on the seat section of the "Tore" chair. One of the older children has a specially-made car seat that she sometimes uses to sit in the back seat with. One of the older children sits in the front seat of the car, which is tilted backwards, without any special seat. This child does not have scoliosis. The other children lie down on the back seat of the car during the trip. In coaches the children sit in their wheelchairs during the trip. All wheelchairs and belts should be checked with the same care as seat belts by the National Road Safety Office.

A question of finance

The families feel that is difficulty financially to have both a large, expensive car and large, expensive accommodation - but both are required in order to manage the child. Although all ten children are entitled to subsidized travel services, the need for the families to have cars of their own is felt to be so pressing that they feel they must have them if they are to manage to look after their children. They therefore feel that cars should be reckoned as aids entitled to subsidies for people (children as well) who cannot use the public transport services that are available to others and which are also often subsidized from public funds.

The majority of the families feel that they need a large five-door estate wagon-type car, like the Volvo 145, with possibly a trailer that they can hitch on when required. Some of the families with the older children find it heavy work to lift the child in and out of the car and lift a wheelchair in and out as well. They would like to have a 15 cwt. van, like a Volkswagen bus, which would allow them to push the child on the wheelchair up a ramp and leave the child sitting in the wheelchair during the trip. It was felt that society should pay for such a van for the older children as it does not seem that public transport, e.g. buses and trains, will be modified for use by the handicapped within the foreseeable future.

The other family could have a cheap, small car for their own use. The family would always have to act as driver for the child, something that is not required by normal teenagers who take the bus or the underground into town, or when they visit friends on their own.

Car conversions

One of the parents would like to have their car modified so that the front passenger seat was reversed enabling the child to sit in it and travel backwards. This would make it easier to drive the car and help the child at the same time. The families require cars

in order to avoid having to plan trips in an abnormal and often impossible way, which is the case when one has to travel using the special transport services for the handicapped. People need to run into to town to shop and perform errands, visit friends, have a day out in the summer, travel to recreational activities with the child, go on holiday, etc. These trips can be spontaneous depending on the weather and how the family feels. These reasons are not accepted by the transport service for the handicapped as justifiable cause for not booking a van at least one day before the trip. In addition it is perhaps not possible for the entire family or a neighbour's children to ride in the vehicles as well. And under these circumstances there is perhaps no point in making the trip. None of these severely handicapped children travel by themselves to their own activities, with the exception of those arranged by the schools.

Even though they have a car of their own, trips involve a lot of work for these families. There is a lot of lifting to do, a lot of luggage has to be taken along in addition to the wheelchair, there is always a lack ot time because it is not possible to change diapers or clothes with the child in the wheelchair. A functional hoist that could be used to lift the child in and out of the car would be a great help for those families who do not want to change their cars for 15 cwt. vans.

If it were possible to dismantle and fold up the wheelchair in a simple way it would be easier to get it into the car and there would be more space for other luggage. If it were possible to use the seat of the wheelchair, suitably adapted to be comfortable, as a car seat (see page) and if the wheelchair chassis could be easily folded up, then these families would have much greater travel opportunities. The "Flexi" and "Ortho" chairs are felt to be too bulky to take in the car and are difficult to take apart. Both the "Hant-

verk" and "Kifa Postura" models are very difficult to transport by car. The "Minimax" and "Max" carriages are felt to be easy to take along.

Special taxi for transportation of the handicapped

The families have expressed the wish that they would like to at least be able to use the special taxis for the transportation of the handicapped as required. Even those families who have cars of their own have a great need to make use of this service on occasion, although they avoid it if possible. Such occasions arise when their car is being serviced or repaired, for example. Parents do not like driving the child alone in the car because of the difficulty of keeping an eye on the child, who may have an attack of cramps, while driving in dense traffic. Some of the mothers do not have driving licences and consequently always have to use the handicapped transport service when the father cannot come along. The same applies when the child has to travel alone or with an attendant who does not have a driving licence.

The families with young children use taxis and in most cases they feel that this works well. Sometimes the taxi has to be booked in advance in order to be sure of getting an estate wagon model. Naturally they would like to avoid having to do this. It is difficult to estimate when one is going to return home when visiting e.g. hospitals or out shopping in town.

Six of the families are not satisfied with the handicapped transportation service. They feel it extremely troublesome to have to book a special vehicle at least one day in advance of the trip. Even estate car model taxis have to often be booked in advance. Families with handicapped children have more difficulty than others in knowing their future plans and consequently have greater difficulty in pre-determining an exact time for a journey. Moreover, several of the families have bitter experience of the unpunctuality of the

service in adhering to the times that have been fixed with a considerable amount of trouble. Being left to wait, perhaps for hours, can be a very unpleasant experience for a handicapped child who is perhaps crying sitting in urine-sodden diapers, with cramps and is also upsetting for the parents. Often the surroundings are unsuitable as well.

Airplanes

Several of the children have used airplanes on occasion. One of them has been on charter flights to the Mediterranean several times. This was successfully accomplished, but was a lot of work for the parents. Now that the child has grown it would be even more work. Long flights would be made easier if the child had a seat section on the wheelchair that could be removed and used on the aircraft seat as a back support.

Boats

The lack of aids suitable for use on boats is a cause of concern. Three of the families have boats in which they usually take their children. In one case the family spends its holiday in a sailboat, the other two make short trips in motor boats. In one of the cases they have to go by boat because their summer cottage is on a small, isolated island. What is needed is a waterproof, modified sitting aid that the child could sit on in the boat (perhaps the seat section of a wheelchair) and very small collapsible chassis to mount it on in order to transport the child when one occasionally goes for a walk. The children like to travel by boat, and the child who vacations on a boat likes sailing and living on board a lot. The parents recounted that the child was in very good health and a wonderful disposition during the entire sailing holiday and the period immediately afterwards. It was heavy work lifting the child in and out of the boat, etc., and they hope to eventually find some form of hoist that will assist them with this.

Cycling

Several of the families get a lot of pleasure from going on bike rides. As things are at present, one of the parents has to stay at home with the handicapped child because they do not have a modified cycle seat or other aid for the child to sit on during a bike ride. Two of the families with young children have been promised "Minimax" trailers for bikes from the handicapped aids centre, with specially adapted seats for the child. They are looking forward to this.

Difficulties during the winter

Several of the families try to avoid going out with the child altogether during the winter when moving around is difficult. This also means that the parents avoid going out together. Most of the families with older children have unwillingly given up hope of experiencing any form of winter sports activity together. Aids are needed to both move the child around in the wheelchair during the winter and to be able to move the child across snow or ice out in the countryside where we others skate, ski or toboggan.

An electrical wheelchair with a powerful form of propulsion could negotiate even snow-covered roads. This aid could therefore solve some of the transportation problems during the winter. But one cannot always take an electrical wheelchair along with one, and it is not always convenient to take it indoors, for example when visiting someone.

Therefore something is required that makes it easier to use an ordinary wheelchair out in the snow. Six of the families are prepared to put skis under the wheelchair during the winter. In such a case a simple attachment device would be required and the skis should also be long enough for the person pushing the wheelchair to stand on, so forming a sort of sleigh.

Putting skis under the wheelchair sufficiently long for the attendant to stand on behind the child converts the wheelchair into a kind of sleigh.

Skis under the wheelchair
Sleigh
Sledge
Carriage

Sleighs

A foam plastic sleigh with room for someone to stand behind and propel the unit forward by pushing down on the snow with one foot, designed to fit the shape of the child, is what one of the younger children, who still does not have a wheelchair, would like. An attempt has been made by one of the families with an older child

to make a box that could hold the child on one of these types of sleigh, to enable the child to be taken along on trips across the ice. The box did not work out so well, but the family would like a well-designed box for this purpose.

Several of the families, particularly those with the younger children, emphasize how important it is for the families to spend their recreational time together. They therefore hope that they will be able to obtain functional aids that make this possible even when the children grow up.

Sledges

Nine of the families feel they have a great need of a sledge for the child in order to get out into the countryside during the winter. Three of the families have sledges that work, the others have none. A foam plastic lining is required for a young child who has an ordinary children's size Laplanders' sledge, which allows the child to semi recline, in order to support the child, and some form of windshield should be mounted on the sledge in front of the child. In order to keep up body warmth the child should be lain in a warm bag, possibly a down sleeping bag on a fur rug.

One of the fathers himself made a fantastic sledge for his child. It is constructed of high-grade timber with fibreglass runners and cannot be tipped over under any circumstances. The child is completely protected in it. It cost a lot to make. The family wishes, in cases like this, that one could at least obtain a grant towards the cost of the materials, when one produces oneself with a considerable amount of trouble and time an aid that would otherwise cost a lot.

One of the older children has a double-sized sledge that he/she semi reclines in, lying in a sleeping bag swathed in sheepskin rugs. Thanks to the sledge the family are capable of taking winter holidays together. One of the parents pulls the sledge when cross-country skiing, or two dogs have sometimes been employed.

One of the families have borrowed a sledge with the help of the handicapped aids centre on one occasion during a winter holiday. They had a "Hasi" bath seat in the sledge which worked. But the parents would like the child to have a sledge the whole winter so that they could take spontaneous trips now and again like everybody else.

Horse riding

It is not impossible for these children to ride or be pulled by a horse if they have the aids for this. Several other members of the children's families are interested in horses and three of the handicapped children sometimes ride horses. As they lack trunk stability it is laborious to hold these children on the back of a horse and an aid - a trunk support or a saddle with trunk support - is required to help the attendant to hold the child. The children like to ride, but they can never learn to ride a horese on their own - they have to be held on the horse and the horse has to be led in a secure way. It is a major experience to feel a large, warm animal such as a horse against one's body and follow its movements when it walks or trots. The horse can go places with the child where a wheelchair cannot go and in this way the children undergo a natural experience they would otherwise miss. One of the children who is blind and deaf lies on the back of the horse in order to obtain as intensive senory impressions as possible from the ride.

RECREATIONAL AIDS

The mobility aids for the children are one of the conditions governing whether the families can get out and experience recreational activities together. It is natural that these families should be able to spend recreational time together, when they can relax, undergo meaningful experiences and occupations together, carry on sporting activities and physical training.

Some of the families have had camping holidays with their children for several years. Tents do not have stairs and ingress with the child is easy. But it is difficult to find room for all the bulky aids that are needed on a camping holiday and it is a lot of work to pack and unpack every time one makes and breaks camp. There should be handicapped aids for camping that are as easy to fold up as other camping furniture and equipment. The situation is that people who can sit without special sitting aids can make use of the ordinary camping furniture and equipment, while those who cannot sit without aids cannot, and therefore have to lie down when on holiday, for example.

We so-called "normal" people have acquired a lot of things to enable us to enjoy a pleasant and rewarding time even outdoors. We have garden furniture, perhaps a swing hammock, hammock, sunshade or similar, perhaps we can use a swimming pool for a refreshing dip, and we have a lot of garden tools to care for the lawn and flower beds. The handicapped children cannot sit in garden furniture or deck chairs, neither can they sit on a swing hammock. There are no lifting aids to get them down to or up from the ground, swimming pool or bathing beach. This means that the parents alone cannot help the older children to experience these places. The children have to stay sitting in their wheelchairs when outdoors and they do not have the opportunity of feeling grass or sand against their bodies.

The heat of the sun

As these children still still when they are outside and do not move around as others, they can experience difficulties when exposed to the heat of the sun. They need to protect their heads and sometimes their entire bodies in order to stay outdoors on hot summer days. As they often sit slightly reclined backwards in the wheelchair they cannot protect their eyes from the sunlight, unless there is some shade available. Several of the children contract cramps from excessive heat and have difficulty being outdoors at all when it is really hot. The parents try and protect the children by placing the wheelchair in the shade of a tree or under a large sunshade in the garden. Nine of the parents would like to have a movable sunshade for the children that could be mounted on the wheelchair, on the edge of a table, etc., and which could be rotated depending on the direction of the sun's rays. It should be strong and robust and it should be possibie to fold it up like an umbrella. It absolutely must not look childish. Several of the families have previously used Mothercare's sun umbrella for infants, but feel that it looks childish, is too small and cannot be properly mounted on the wheelchair.

If a functional sun shade were available, that could be mounted on e.g. a wheelchair and other protrusions, then the child would not have to always sit in the same places outdoors when the sun was shining. It would be possible for the child to go anywhere in the garden, to go to the beach, go along on boat trips, go for walks, etc., without running the risk of the ill effects of the sun and the heat.

Outdoor bathing

Some of the children require floatation aids if they are to be able to bathe outdoors or in swimming pools. According to the parents the children would bathe outdoors more often if they could be sup-

ported by a non-tippable ring or similar, which would facilitate holding them up in the water. The children would find it easier to play in the water, making their own movements and experiencing for themselves how it felt without having to hold on to their parents all the time.

One of the children has never bathed, either outdoors or in a swimming pool, but will soon be making the occasional trip with the school to a swimming pool. As the child does not have stability of the head a floatation aid is required that does not just provide support under the arms but holds the head above water as well. Three of the six children who require floatation aids use ordinary, large-size inflatable rings which work well.

One of the children needs an air bed to lie face down on at the edge of the water in order to be able to enjoy an ordinary outdoor swimming area. The child felt the water was too cold, but was very interested in looking around and feeling the water. One of the children requires a double air bed to lie on to avoid the heat from hot rocks. An ordinary air bed is too narrow and easy to slide off. One of the children has an inflatable rubber dinghy which can be used at the beach and in the water.

The children have difficulty in making use of the collective play areas available in the areas where they live. It is not possible for them to ride swings, sit in sand pits or climb on climbing frames or up rope ladders. They cannot ride on roundabouts or play hopscotch. One of the children has a swing outdoors made from "Klippan" car seat that is suspended from a tree. All children like to swing and it should be possible to find a swing like the car seat one or some form of trunk support to put on an ordinary swing.

Swings

It was suggested that a swing seat frame for customized foam plastic armchairs be produced. It should also be possible to make a swing seat frame for other types of seats, such as the "Klippan" car seat, for those children who do not have scoliosis. Perhaps it should be possible to adjust the height of the frame so that the children can reach the ground with their feet and kick the swing into motion. None of the children can swing using their bodies as normal children do. Swinging is a good way a giving pleasure to deaf/blind children and children with these handicaps need a functioning swing. The child in question in the survey is now so big that he/she is too heavy to swing sitting on someone's knee. A pair of overalls supporting the entire body or a trunk and head support which is individually designed for the older children, would be suitable for them to hang and swing in. It should be possible to use these supports on both indoor and outdoor swings.

Swing hammocks and hammocks are other forms of swings used by some families. The child lies down and swings and likes it. Making a baby walker that is suspended from a ceiling-mounted hoist was described on page 72. It should also be possible to use the hoist to suspend a swing in a similar manner. It would then be possible to adjust the height so that the child's feet were at the desired height.

The parents believe that trying Lilli Nielsen's pedagogic methods might help to activate the children who are unwilling to use their hands themselves. There is a considerable risk that these children become under-stimulated because it requires a lot of time, patience and imagination to find something suitable for the children to do. Several of the older children were more active when young than they are at present. Previously one of the children used his/her hands a lot to throw things around and explore the surroundings. After a stay in a summer camp for a few weeks all spontaneous activitiy by the child disappeared to be replaced by stereotype movements. Since then the child has never used his/her hands to do things.

Using the hands

The children need toys that provide a lot of sensory impressions and which produce substantial results from small movements made by the child. In addition to the ideas and wishes already expressed by the parents, the following can be mentioned:

A piece of flat board with hinged mounts on which all imaginable sorts of things can be attached so that even blind and severely spastic children can feel them without them being knocked off when they are touched. Also a board with various keys that flash, ring, rattle or honk like a horn, etc., when lightly touched. This would stimulate the children to use their hands in order to get something exciting to happen.

The role of music

The families have record players and the children are extremely fond fo listening to certain records. Several of the children like making music themselves. One of the children often plays a guitar or zither. Two children have electric organs which emit sounds when touched lightly without having to depress the keys. Pushing a button produces background rhythms which gives a substantial effect from a small movement from the child. All the children like some musical instruments. The deaf children feel the vibrations from drums when they are given help to beat a drum with their hands. The young children and some of the older ones use strings of bells with clear, pure sounds that are tied round the wrist or ankle. Different types of rattles are also interesting, but are often difficult for the children to keep a grip of.

It is important that it sounds good when the musical children try to play, otherwise they are not motivated to try again. One of the children clearly indicates that he/she would prefer the mother to play pretty tunes rather than try to play him/herself. A musical box with a pretty tune which plays when the child holds it can better

motivate such children to play themselves.

One of the children who does not want to use her hands at all has several musical boxes with pleasant tunes to look at and listen to when someone winds them up for her. Her father bought the musical boxes in Japan. Typically, such a box has a brightly painted Japanese doll on the top which rotates while the box plays a clear, little tune.

None of the children can clap their hands to music or play traditional, simple instruments that have to be held in the hand. They cannot blow. But the children can be helped to clap in time with music by holding their hands and holding an instrument such as a tambourine which is played with them. Naturally this requires the help of another person.

Toys

Seven of the families believe that their children would get a lot of pleasure from electrically-powered toys that could be operated by simple movements without having to be held or pressed.

For example, a model car track that could be operated by a large, touch-activated switch. In the same way the children could operate modified muscial boxes and, as mentioned earlier, TV sets, radios and tape recorders, as well as turning lamps on and off.

Physical exercise is very important for these children. They can neither jog nor play squash, but the undergo physiotherapy and their body positions are varied so that their internal organs, etc., are not subjected to uneven loads. They need to stand up, for instance, in order to put load on their skeletons so that they do not lose their calcium contents. It is important that the children receive physiotherapy and get help to work with their muscles. For example,

scoliosis can be counteracted by the children strengthening their back muscles and stretching out their spines as often as possible. The physiotherapist is a very important human aid for these children and helps them to fight against contractures and a worsening of the scoliosis, together with keeping their bodies in physical trim.

Tipping board

The children require technical aids to enable them to change position. Most of the children have a tipping board, for example. Standing upright with this board gives the children another view of their surroundings. The most usual is that the children have a stomach-height tipping board that enables them to have their arms in front of their bodies while they are in a vertical position on the board. All the parents think that the tipping boards are complicated and take up a lot of space. Instead they would like a specially-designed frame (board) that can be leant against a table or be laid on the floor where it would serve as a simple wedged-shaped support. Loose cushions and complicated straps should be avoided if possible. A tipping board must have a little chassis to get through doorways which should, if possible, be removable when not in use to save space, if one is to have such equipment at home. It is difficult and heavy work to get a grown-up child onto a tipping board. Even if there is hoist available, it cannot be used to get a child onto a stomach-high tipping board, and the children cannot be rolled over from their backs onto their stomachs on the tipping boards they have. What is required is a stomach-high tipping board which allows the child to be positioned using a hoist, so that two adults are not required to help the child.

One of the parents wants a large table on which to lay the child, in order for him/her to be at the same level as everybody else in the room and so that the parents do not have to lie and crawl on the floor in order to play, work or socialize with their child. This

The parents would like a large table for their children which would put them at the same height as other people in the room. The table should be sufficiently large to accommodate a Lilli Nielsen board (resonance board). Lilli Nielsen is a Danish child specialist who works with questions of methodology and aids, particularly for mentally retarded children with severe visual impairment. The "board" is a large sheet of chipboard or plywood on which the child is placed. The resonance board is so sensitive that every movement the child makes results in a certain reaction which the severely handicapped child has the chance to influence.

Camping aids
Bathing ring
Toys
Board
Training aids
Sun shade
Suspended overalls
Electrically-powered toys
Large table
Trampolin

large table would have drawer pedestals underneath for toys, etc., and would be sufficiently large to accommodate a Lilli Nielsen board on top. The blind child is in great need of the type of stimulation that this board provides.

Support for the arms

The other training aids the children can require are a gymnastics mat and a "Bobath" ball, for example. Several of the children do have such a ball which the physiotherapist and the parents use to in exercising the children. The children like this sort of excercise a lot. Unfortunately the ball is a bulky item to have in the home, it often disintegrates and needs replacement. Some of the older children are heavy and difficult to get up onto the ball with the result that some of the parents no longer can manage to give their children this type of exercise. The majority of the children require some support for the arms which also raises the upper body and permits them to lie on their stomachs and play or to strectch their spines. Wedge-shaped cushions or rolls are used underneath the chests of children who otherwise could not support themselves on their elbows and hold their bodies straight. The rolls are of various sizes and are made of foam plastic with PVC covers. They can also be used during breathing exercises, etc. The wedge-shaped cushions are also made of foam plastic with PVC covers or the "Rehab Wedge" is used to lie the child on. This is a wedge-shaped cushion comprising a pipe frame and canvas upholstery. The pipes that the cushion rests on run laterally in front of and under the children in an unsuitable way so that they chafe them on their elbows and knees when lying down. The parents feel that these pipes should instead run parallel to the children's bodies so that they could make crawling movements without hurting themselves.

Gymnastics

Several of the children often lie on their stomachs to straighten their spines. One of the children who has a hernia feels less pain from this if she lies on her stomach than on her back or sits, but another child with a hernia cannot lie face down at all because haemorrhaging becomes more likely. The children can hardly use any of the traditional gymnastic equipment that our gymnastic and sport facilities are provided with. But a trampolin to bounce and swing the children on would certainly give most of them pleasure, and several parents feel that the training schools should have such equipment. Pehaps some of the children could benefit from gym shoes with special soles that give more speed when one kicks or swings if they had the chance to participate in such activities.

HOISTING AIDS

The ten children belong to the category usually described as very difficult to look after. This argument is often used by those who feel that it is impossible to look after people with such severe handicaps in the home, or those who feel that it is actually unsuitable to even try. It is felt that there has to be several people involved in providing care, at least for the older children. The children need to be lifted, and lifted often, throughout the course of the day and night. This is one of the most laborious operations in the work of providing care and in some cases it is impossible for one person alone to perform this work over a long period of time, unless there is an operational hoisting aid available.

The eight oldest children in the survey need hoisting aids in various situations. Five of them have one or more "Akema" ceiling-mounted hoists installed in the home. Only one of the families uses this regularly. That this figure is so low is due to the others not having received harnesses for the hoists that work. Otherwise it is felt that the actual hoist machinery itself is reliable and serviceable. The families wished that it had a better appearance, was more discreet and looked less like hospital equipment. That it was quieter in operation and the cables and the suchlike hanging from the ceiling could be avoided. In order to be of use it must be rapid and simple to operate. And it must reach right down to the floor for the most laborious lifts. The families who have had the "Akema" ceiling-mounted hoists installed have experienced difficulties with the positioning of the hoist tracks. Too late, they have realized that they have been supplied with tracks that are far too short, or which are too close to walls or which do not reach the correct places, e.g. over the bath tub.

A feeling of being a care recipient

human beings are required to manoeuvre all the types of hoists for the children. The children cannot use the hoisting aids themselves but the hoists do enable them to avoid being with a lot of people when they need to be alone, e.g. when performing personal hygiene. It is easy for several people who are working with a child to talk round the child, with the result that the child feels like a person receiving care.

Most of the parents have to be able to look after the children on their own during the day. Parents without operational hoists therefore wear out their backs - several experience periodic back pains. In addition to being able to have electrical ceiling-mounted hoists strategically positioned, the families need a mobile manual hoist which can be easily folded up for stowage and transportation. It must be able to lift a child from a wheelchair down to the floor/ground without having to readjust the harness in order to make it serviceable for these families. At present it is lifts from the ground, for example, that are such hard work because none of the families have found a hoist that can cope here.

Such a manual hoist is also required when on holiday trips, lifting in and out of the swimming pool and in rooms in the home where there are no ceiling-mounted hoists. These hoists have to be designed so that the child can be held with one hand and the hoist operated with the other.

Lifting the child in and out of a car is complicated and difficult because the child has to be lifted while being inserted or extracted from a restricted space. Five of the families need a simple hoist that could, for instance, be attached to the car door to lift the child out of the wheelchair and onto the car seat. This would make it easier to use an ordinary passenger car more often and special

transportation vehicles for the handicapped less. The child would certainly be taken along more often on shorter trips. For example, as things are at present it is hardly worth the major lifting effort to take the child along to do the shopping. The child and the wheel-chair have to be lifted into the car at home, out again on arrival at the shops, in again after shopping and back out on return home. It is easier to get a child-minder, if possible, while one does the shopping, but then the child misses the important experience of going along and finding out where the food they have at home comes from.

Unusable harnesses

A 15 cwt. van, like the Volkswagen, can solve the problem of lifting in and out of cars, but none of these ten families have given up hope of being able to use ordinary passenger cars like everybody else.

All the hoists for the children have to have operational harnesses in order to function. This seems to be the most difficult thing to arrange for those families who have "Akema" ceiling-mounted hoists installed. Only one of the families feels that the harnesses they have for the child are of practical use. But even this family would like to see improvements because the harness is complicated to put on and take off. The families feel that very much simpler harnesses would work. In some cases they would like to try straps that could easily be put on and taken off the child, both under the back at the bend of the arm and under the legs at the hollow of the knees. This enables the parents to lift the children in their own arms.

They also need water-resistant, soft harnesses/straps that can be used in the shower or bath to enable the hoisting aid to be used for one of the worst lifts, namely in and out of the bath tub. The shower and bath harnesses must be such that the whole of the

child's body can be washed with them in position. The design of harness that requires the child to be lifted in order to get the harness underneath is not a lot of help.

Ramps

We have steps, ladders, bridges and piers, lifts, escalators, ski lifts and cable cars, to mention just a few examples, to help us get to different heights both indoors and out.

People in wheelchairs cannot use many of these devices. We could climb up to most places without recourse to aids but those who cannot walk or climb need aids to manage this. One aid that is required is, for example: a lightweight, extendable ramp that could be placed over small changes in height, like steps. Most of the families require such an aid because at present two attendants are required to get a wheelchair with child up or down even a few steps. The ramps should be made of lightweight metal that does not make a rattling noise when being transported by car and should not have sharp edges which can cause injury when handling the aid. These ramps could be used on holiday to negotiate steps into the summer cottage, for instance.

The families need a sufficiently large elevator in order to be able to move between the different floors of a block of flats, with room for both the wheelchair and the attendant. An electrical lift is required in the stairwell in order to be able to move between floors. A plate that could lift the wheelchair, with the child in it, up a flight of stairs. The attendant could walk at the side.

Chair lift

One of the families has a chair lift on the stairs to the upper floor of their house, but it is complicated to use. It consists of a little chair that runs up the stairs on a track. The child cannot

sit on the chair so the child is moved to the upper floor as follows: Both parents lift the child out of the wheelchair, one of them sits on the chair lift with the large child on his/her lap and rides up the stairs, then both parents help to lift the child into a wheelchair that is kept upstairs. Despite all the trouble the family are glad to have this chair lift. Previously it was even more difficult to get up the child up the stairs without it. The families who live in two-storey houses need a plate that could travel up a flight of stairs with the child sitting in a wheelchair.

A manual elevator arrangement that could easily be mounted on the stairs, for example, is required for temporary or other visits in homes on the upper floors of buildings without lifts in order to lift up the children to that floor. Perhaps such a device could be simply constructed from a block and tackle?

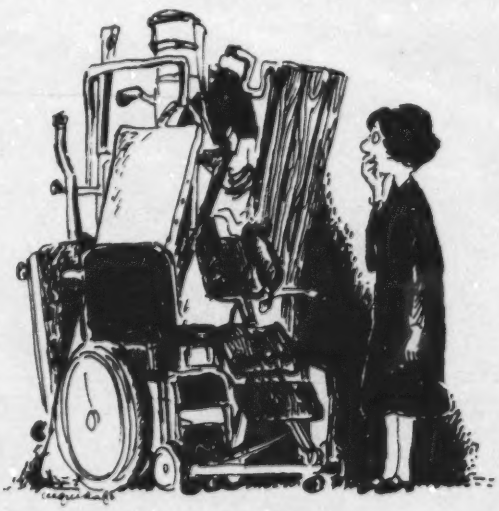
One of the families spends the summer in the upper floor of a house on an island without electricity. They need such a simple type of hoist. They have thought about designing something along these lines that would allow the child to be raised up in a cloth bag through an open space to one side of the staircase. Their ability to take the child to the island for the summer is dependent on them being able to make this work.

Harness
Ramp
Elevator arrangement
Stair lift

THE APPEARANCE OF THE AIDS

The parents emphasized the importance of the design of the aids. An aid that acts as a piece of furniture should look like a piece of furniture and should fit in with the rest of the furniture in the room. Shiny, hospital-like aids are not welcome in a home. A large choice of colours and fabrics was also requested.

It was striking how the parents of the older children have become used to being surrounded by things that had a handicapped appearance - they were so happy that the aid worked. They have often given up the demand that they should also like the way the aids looked. The parents of young children emphasized much more frequently the importance of the aids having a certain appearance in order for them to be acceptable in the home.



The older the child the more room the aids take up in the home. It should therefore be possible to combine as many aids as possible. It should also be possible to fold them up and dismantle them when not in use.

Storing the aids

As these severely handicapped children have such a great need for a large number of different aids, they take up a lot of room in the home. The amount of space required grows with the child. In order to counteract this it should be possible to combine as many of the aids as feasible and use them for more than one purpose. Where feasible it should be possible to fold them up or take them apart to enable them to be stored in cupboards, etc., when not in use.

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The Swedish Institute for Disabled Persons

The Swedish Institute for Disabled Persons is the central body dealing with aids for the disabled. The Institute performs surveys, R&D, testing, information dissemination and training concerning handicap aids and infrastructure planning for people with reduced capabilities. The Institute adapts vehicles and manufactures devices for disabled drivers. The Institute is financed by central and local government authorities.